CHAPTER 1

An Overview of Pediatric Obsessive–Compulsive Disorder and Its Treatment

What Is Pediatric OCD?

Obsessive–compulsive disorder (OCD) is one of the most debilitating mental disorders of our era, with half of cases striking in childhood (Westwell-Roper & Stewart, 2019). Delays in proper diagnosis and treatment of this disorder often extend over months or years. And, when left untreated, OCD tends to worsen due to negative reinforcement, leaving in its wake disrupted development, impeded academic and career achievement, and relationship difficulties (Fineberg et al., 2019). Yet, OCD has been proven responsive to skillfully conducted evidence-based treatment (Dougherty et al., 2018). Thus, despite being a severe illness, OCD is highly rewarding to treat given its potential for dramatic improvement within a limited time frame.

OCD Is Common

In the National Comorbidity Survey Replication, over one quarter (28.2%) of respondents reported having had an obsession or compulsion in their lifetime (Ruscio, Stein, Chiu, & Kessler, 2010). A smaller proportion of individuals in the population (1–3%) have full-blown OCD, involving functional impairment, significant distress, or notable time spent consumed by symptoms.

OCD Symptoms Are Diverse (and Often Misdiagnosed)

OCD is possibly one of the most misunderstood and underestimated disorders by the general public, given the familiarity of symptoms in their mild form (e.g., checking that a door

is locked, washing hands in a particular pattern). The expression "I'm SO OCD" is both common and misleading, falsely suggesting that OCD is a positive personal characteristic rather than a debilitating, time-consuming, and biologically driven disease. In contrast to many other mental illnesses, OCD has symptom types that are very numerous and diverse. The Children's Yale–Brown Obsessive Compulsive Scale (CY-BOCS) checklist provides a list of over 70 symptom types across 13 categories of obsession and compulsion (Scahill et al., 1997).

In addition to the frequent co-occurrence of symptoms at a specific point of time, OCD symptoms in any given individual often change over the course of illness. A notable area of research interest has examined co-occurrence of OCD symptom types, known as symptom dimensions, within clinical and population samples (Stewart et al., 2008; Bloch, Landeros-Weisenberger, Rosario, Pittenger, & Leckman, 2008; Alvarenga et al., 2015).

Primary symptom factors or dimensions identified in pediatric OCD are as follows:

- *"Classic" OCD symptom dimension:* Contamination and somatic obsessions and cleaning compulsions.
- *"Intrusive thoughts" OCD symptom dimension:* Aggressive, sexual, and religious obsessions.
- *"Just-right" OCD symptom dimension:* Symmetry obsessions, ordering, repeating, counting, checking, and hoarding.

Symptom dimensions identified in adult OCD are very similar to those in pediatric OCD, with the exception that somatic and checking symptoms both move to the "bad thoughts" dimension, from the "classic" and "just-right" dimensions, respectively (Bloch et al., 2008). Moreover, "just right" and hoarding symptoms occupy separate factors in some related analyses.

While it was previously believed that limited insight is the "norm" in pediatric OCD, a recent meta-analysis by our team and international colleagues found that almost 90% had insight ranging between fair and excellent (Selles et al., 2018b).

OCD Comorbidity

Co-occurrence of additional mental illnesses are the rule rather than the exception in pediatric OCD. More than half of cases in epidemiological samples have at least one such comorbid illness (Flament et al., 1988). Comorbidities associated with earlier OCD onset include anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), and tic disorders, whereas those associated with older OCD onset include mood and psychotic disorders (Geller et al., 2000).

OCD "Look-Alikes"

When a child or youth presents with repetitive behaviors or recurrent distressing thoughts and a presumed OCD diagnosis, it is important to ensure that these do not solely represent other

diagnoses before proceeding with OCD-focused treatment approaches. Other childhood-onset illnesses with repetitive behaviors presenting as core symptoms include tic and autism spectrum disorders. Impairing adolescent-onset repetitive behaviors often present in the context of eating or obsessive–compulsive-related disorders (OCRDs; Coelho et al., 2019; Westwell-Roper & Stewart, 2019).

Alternative diagnoses to consider when assessing youth who present with distressing thoughts, related impairment, and presumed OCD include anxiety and psychotic disorders. However, due to OCD-driven secrecy, magical thinking, and the "oddness" of certain rituals, misdiagnoses between OCD and first-episode psychosis are too common, especially among adolescent males.

Specific, Complex, and Dramatic Acute-Onset Presentations

An OCD-related topic of controversy and recurring media attention over the past decade and a half relates to pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS) (Murphy, Gerardi, & Leckman, 2014). These are implicated when rapid and dramatic emergence of OCD (or tics or food restriction) occurs with a cluster of other newly occurring "non-OCD" symptoms. They have been noted to occur in 2–5% of pediatric OCD cases (Jaspers-Fayer et al., 2017). Parents are particularly vulnerable, as related family impairment is significantly higher than that in non-PANDAS/PANS cases of OCD (Jaspers-Fayer et al., 2017). Unfortunately, families seeking help often receive contradictory and alarming advice from professionals, paraprofessionals, and Internet sources with respect to best assessment and management of these presentations.

Diagnostic criteria for PANDAS and PANS are as follows:

PANDAS

- OCD and/or tic disorder
- Pediatric onset—between 3 years and puberty
- Abrupt onset or dramatic symptom exacerbation with a sawtooth course
- Association with a confirmed streptococcal infection
- Association with other neuropsychiatric symptoms (e.g., choreiform movements)

PANS

- Abrupt, dramatic onset of OCD symptoms or severe food intake restriction
- Concurrent, sudden onset of at least two of the following symptoms:
  - Anxiety
  - Emotional lability/depression
  - Irritability
  - Aggression and/or oppositional behaviors
  - Behavioral (developmental) regression
  - Deterioration in school performance

  - Sensorimotor abnormalities
  - Somatic signs and symptoms
- Symptoms not better explained by a known neurological or medical condition

OCD Often Begins in Childhood

OCD tends to emerge earlier in boys than girls. In males, onset peaks occur between 8 and 10 years, 18 and 22 years, and during the late 20s (Ruscio et al., 2010). In females, many cases onset between 20 and 30 years of age. These may coincide with periods of hormonal shifts that impact brain development and with times of major life transitions. While some cases of new OCD onset are reported in the elderly, this is uncommon.

It has been suggested that childhood-onset OCD may represent a distinct subtype of the disorder (Chabane et al., 2005). This group has higher rates of comorbid tics and ADHD. In addition, the role of genetics appears to be stronger in the childhood-onset form, being responsible for approximately 45–65% of attributable risk, compared to 27–47% in adults (van Grootheest, Cath, Beekman, & Boomsma, 2005). However, despite international efforts, no specific OCD risk genes have been confirmed (Dougherty et al., 2018).

OCD Symptoms and Avoidance Are Debilitating

It is estimated that an average of 3 years of wages are lost over the lifetime of those with OCD due to this illness (Hollander & Wong, 1995), and that those experiencing OCD spend an average of 10 hours a day engaging in OCD symptoms (Ruscio et al., 2010). Quality of life (Coluccia, Ferretti, Fagiolini, & Pozza, 2017), sleep (Jaspers-Fayer et al., 2018), athletic (Cromer, Kaier, Davis, Stunk, & Stewart, 2017) and academic function (Negreiros, Belschner, Selles, Lin, & Stewart, 2018; Perez-Vigil et al., 2018) are also negatively impacted by OCD. Fortunately, prompt intervention and treatment in childhood and adolescence can positively impact the long-term trajectory of OCD and enhance the well-being of children, youth, and families impacted by OCD (Fineberg et al., 2019).

OCD Prognosis

While adult OCD has historically been considered a chronic diagnosis, facts suggest that the childhood-onset form of this illness (especially when associated with tics) has a better long-term prognosis (Bloch et al., 2009). Based on independent study samples, less than one-half of children (41%) have ongoing OCD at long-term follow-up and approximately 20% have only nonimpairing OCD symptoms (Micali et al., 2010; Stewart et al., 2004). Of interest, it is not severity of OCD symptoms, but rather the duration of illness prior to assessment that predicts persistence (Stewart et al., 2004; Melin, Skarphedinsson, Skärsäter, Haugland, & Ivarsson, 2018). Thus, it is important to emphasize to parents (and to clinicians!) that early recognition and intervention are important to optimize their child's outcome. This has been emphasized in a 2019 international expert consensus statement (Fineberg et al., 2019). In addition, it is crucial to remember that OCD can be well managed despite occasional, intermittent recurrence of symptoms.

Family Accommodation and Impacts

While all childhood illnesses have an impact on families, pediatric OCD is especially impairing. OCD symptoms frequently involve and demand participation or accommodation by family members and others living in the home. In fact, over 90% of OCD-affected families report accommodating to either prevent or relieve their relative's OCD-triggered distress (Stewart et al., 2008).

Family accommodation includes compulsion facilitation (e.g., listening to "confessions"), reassurance giving, and enabling avoidance of triggers (e.g., abstaining from saying certain words; Peris et al., 2008). Although well intentioned, family accommodation inadvertently worsens OCD symptoms and is associated with increased disease severity, higher functional impairment, and poor treatment response (Storch et al., 2007a). While family accommodation behaviors are often performed without awareness of their negative impacts, even engaged and committed parents frequently struggle to resist accommodating in acute situations due to the difficulty of tolerating their child's acute OCD-related distress.

Regardless of family accommodation, general impacts of OCD on family life are extensive (Stewart et al., 2017). The burden on caregivers of adults with OCD is comparable to that of caregivers of those with schizophrenia (Thomas, Suresh Kujmar, Verma, Sinha, & Andrade, 2004). Moreover, burden and negative impacts on quality of life have been noted for parents of OCD-affected youth (Wu et al., 2018).

The family activities most commonly impacted by childhood OCD include morning and bedtime routines and mealtimes. Compared to families of those with clinical depression, families of OCD-affected individuals experience greater illness burden and more impaired functioning, partially due to the increased expressed anger when illness-related demands are not accommodated. Nearly one-half of mothers and a third of fathers report daily impacts on their jobs due to their child's OCD symptoms. Moreover, over half of parents reported that they often or always feel anxious, frustrated, and saddened by their child's OCD.

Treatment of Pediatric OCD

OCD Improves with Treatment

OCD-affected families and their clinicians are currently in a much better position than their predecessors 30–40 years ago. This is thanks to a plethora of pediatric and adult OCD studies demonstrating the efficacy of both cognitive-behavioral therapy (CBT) and serotonin reuptake inhibitor medications, including selective serotonin reuptake inhibitors (SSRIs) and clomipramine (Bloch & Storch, 2015).

The Pediatric OCD Treatment Study (POTS) is the landmark study comparing medication, CBT, and combined approaches with placebo in pediatric OCD management (Pediatric OCD Treatment Study Team, 2004). The CBT treatment regimen involved 14 1-hour therapy sessions over 12 weeks, including psychoeducation, cognitive training, OCD symptom mapping, and exposure and response prevention (ERP). The latter component represents a core element in the psychosocial treatment of OCD and involves having the child or

youth gradually and systematically confront their feared OCD triggers *without* engaging in the rituals that previously were employed to reduce anxiety or other distressing emotions that the stimulus caused. With repeated exposure, the child habituates to the stimulus and the urge to engage in the ritual dissipates. Reported remission rates and number needed to treat (NNT) data (number of individuals required to receive treatment to expect OCD remission in one individual) were as follows: sertraline (21%, NNT = 5.6); CBT (39%, NNT = 2.8); and combined sertraline + CBT (54%, NNT = 2.0), versus placebo (4%). While some debate remains with respect to the relative efficacy of combined treatment (CBT and medication) versus either CBT alone or medication alone in pediatric OCD, a consistently replicated fact is that CBT (with and without medication) is statistically and clinically superior to placebo (Westwell-Roper & Stewart, 2019).

OCD Is Rewarding to Treat

OCD is a rewarding condition to treat, with frequent success stories and happy, very grateful families. However, the complexity, changing nature, and subtlety of OCD symptoms can provide challenges to provision of high-quality CBT. There is no "one-size-fits-all" approach, and clinician skill and creativity are assets when developing ERP activities. This fact was demonstrated by the results of the POTS trial, which reflected the importance of individual CBT skills as an influence on outcomes. Specifically, observed treatment effect sizes differed notably across sites for CBT (0.5–1.6, ranging widely from medium to very large effect), whereas this was not found for sertraline (0.5–0.8, medium effect across all sites).

While OCD recognition and diagnosis have improved, and while ERP is clearly proven for use across the life-span, sadly only a minority of affected individuals access this treatment. One of the largest barriers to access has been created by limited availability of CBT providers trained in ERP for OCD. This book has been written in an effort to increase the confidence and willingness of CBT-trained clinicians to embark on the rewarding journey of becoming an OCD therapist!

How ERP works

ERP has long persisted as the most effective therapeutic approach in the treatment of OCD. It appears that there is more than one mechanism by which improvements occur, including both habituation and inhibitory learning (Hezel & Simpson, 2019).

The treatment program presented in this book, and in leading pediatric and adult OCD CBT books historically, is largely based upon the premise that a process called habituation is at play. This idea, as proposed by Foa's emotional processing theory, states that exposures work when the fear or distress evoked by a stimulus (i.e., "fear response") decreases as that stimulus is repeatedly presented (Foa & Kozak, 1986). This may occur both within and between practice sessions. Guided by this theory, traditional ERP paradigms involve systematic exposure to progressive, increasingly challenging stimuli after each has been "mastered" (i.e., has lost the ability to trigger a fear response).

Recent years have added clarity regarding ERP mechanisms in OCD. Driven by the formidable work of Michelle Craske (e.g., Craske, Treanor, Conway, Zbozinek, & Vervliet, 2014), inhibitory learning (IL) theory suggests that the initial fear response is not extinguished, forgotten, or unlearned. The fear response continues to be evoked. However, during exposure, a tolerance of the subsequent experience of discomfort or distress occurs, and this new response inhibits or overrides the old response.

So, how does this impact specific aspects of ERP treatment for OCD or anxiety? Discussion of habituation versus inhibitory learning mechanisms is more than only theoretical. As noted, a spirit of creativity, curiosity, willingness to learn, and persistence through iterative trial and error are tools used by the best OCD ERP treatment providers. It is likely that both extinction and inhibitory learning are in play during ERP.

Some children do not report progressive decreases in anxiety with ERP. From an IL perspective, this does not necessarily mean the therapy is not working, given that new learning is still taking place. What the children or youth may be developing in these cases are new expectations of how bad the feared stimulus will be and how capable they are at tolerating the related distress. For these children or youth, measuring numerical ratings of distress (subjective units of distress [SUDs]; see Module 1) is not particularly useful, nor is working on a graduated fear ladder. Instead, varying the intensity of exposures and the settings in which they occur may promote more generalization of the learning process.

Of note, most of the modules in this book are based on emotional processing theory and habituation. Module adaptations based on IL theory as described previously may be used as deemed appropriate, especially for cases in which habituation does not appear to be occurring.

Generalizing ERP Successes

An important aspect in the treatment of pediatric OCD is the generalization of gains made in the treatment session to the regular life environment. While it is wonderful when a child or youth is able to touch door handles in the office and to resist handwashing for the first time, that does little to impact day-to-day functioning if similar gains do not extend to their home, school, or community. For this reason, ERP exercises are often most effective when conducted outside of the clinician's office. This can include completing ERPs while riding public transit with a child or youth, visiting public restrooms together, visiting places of worship, or having them touch contaminated objects in their home.

Every clinician may not have the capacity to complete ERPs outside the office, either due to geographical limitations or occupational restrictions. One way to overcome this barrier is to have youth and families bring in obsessional triggers from home (e.g., contaminated clothing, a Bible, items that need to be organized in a specific way) and to use them in session. Similarly, between-session homework can be developed so that children or youth have opportunities to complete ERPs in a variety of triggering settings. For example, if they have difficulties touching bathroom taps, then over the course of treatment they should be completing ERPs that include touching taps at home, at friends' houses, at the mall, and at school (depending on identified related obsessional triggers). Families should be asked to

plan on dedicating at least a half hour of homework each day to focusing on exposures and response prevention. For some families, this may necessitate helping parents to carve out time by eliminating selected extracurricular activities during the active treatment period.

When to Consider Alternatives or to Temporarily Delay ERPs

A majority of children and youth respond positively to ERPs and experience a decrease in OCD symptoms through processes that likely include habituation or inhibitory learning, as described previously. While it is impossible to predict outcomes for individual children or youth, certain identifiable factors influence the likelihood of CBT success.

A recent systematic review found that comorbid tics and a family history of OCD moderate CBT treatment response in pediatric OCD (Turner, O'Gorman, Nair, & O'Kearney, 2018). Compared to placebo response rates, children with tics were more likely to respond to CBT alone but not to an SSRI (sertraline) alone. However, for initial CBT nonresponders, the presence of tics favored addition of sertraline over continued CBT alone.

Those with a family history of OCD were more likely to respond to CBT combined with an SSRI (sertraline), but not to CBT alone. Other factors associated with poorer CBT response included older age, OCD severity, comorbidity, and increased family accommodation. The following may be a helpful guideline for individual cases. Appropriate treatment includes reduction of avoidance and family accommodation, and:

- Mild OCD → CBT alone
- Moderate to severe OCD:
  - Family history of OCD → CBT + SSRI
  - Comorbid tics → CBT alone → if non-response, add SSRI
  - No OCD family history or comorbid tics → CBT ± SSRI

For a small percentage of OCD-affected children and youth, significant and risky maladaptive behaviors may emerge or worsen in the context of ERP treatment. Those with uncontrolled patterns of behavior including self-injurious acts, violence, suicide attempts, or substance use may turn to these as a means of coping with ERP-triggered distress. Blindly continuing to encourage ERPs for these individuals without adequate emotion regulation skills and adaptive coping is unwise, as treatment will likely further exacerbate unsafe behaviors. Continuing will effectively distract from OCD treatment targets and enable avoidance. In such circumstances, it is often best to suspend ERP and shift the focus to adaptive coping and emotion regulation skill development. This may involve utilizing a dialectical behavior therapy (DBT)-informed approach or referring the individual to a DBT specialty program, with a long-term plan to return and engage in OCD-focused ERP. However, it is important to send a message to the family that the long-term goal is for the child or youth to eventually engage in ERP, once they have developed the skills necessary for this challenge.

Being Aware of Inappropriate (and Potentially Therapist-Related) ERP Delays

Despite the potential problems noted above, it is important to not "enable" ongoing delays leading up to ERP initiation. In our experience, it is far more common for therapists to spend inappropriately long periods of time prior to initiating ERPs while conducting background assessment and supportive therapy than it is for them to begin ERPs inappropriately early. Baseline factors such as limited insight and the presence of coercive behaviors have historically been identified as reasons to be skeptical about potential ERP success. However, these notions have been challenged by findings that both coercive behavior and insight level tend to improve with ERP in childhood OCD (Selles et al., 2018a). In fact, improvement in coercive/disruptive behavior predicts OCD severity and individual and family functioning improvement (Schuberth, Selles, & Stewart, 2018). Moreover, the presence of poor insight does not appear to predict CBT nonresponse, although the absence of insight does predict CBT dropout (Selles et al., 2019).

Delays to initiating ERPs may also reflect therapist hesitancy and unwitting avoidance of the inevitable related distress witnessed in the youth, and at times experienced by the therapist. While it is natural for therapists (who have committed themselves to a career of helping others, after all!) to hesitate prior to ERP initiation, it is important to not overvalue the meaning or true danger of OCD-related distress. Such delays may signal to the child or youth (and parents) that they are not strong enough to face up to the OCD bully.

Overview of the "OCD Is Not the Boss of Me" Treatment Program

Part II of this book consists of 10 treatment modules covering a variety of topics in the treatment of OCD, with primary emphasis on ERP techniques. The module topics are as follows:

- Module 1: Treatment Preparation with the Child or Youth and Their Parents
- Module 2: Explaining ERPs, Building an OCD Ladder, and Implementing Rewards
- Module 3: Foundational Treatment Tools
- Module 4: Breaking OCD's Rules
- Module 5: Tools to Help with OCD "Bad Thoughts"
- Module 6: Tools to Help with ERPs
- Module 7: Troubleshooting ERPs
- Module 8: Self-Care and Family Care
- Module 9: Preparing for the Future
- Module 10: Graduation

These modules are designed for flexible use with children, youth, and families to allow for an individualized treatment approach. When initiating treatment, it may be most helpful to proceed in chronological order through the modules, recognizing that some modules may

be covered in a single session whereas others may require multiple sessions, as influenced by symptom presentation, treatment engagement, and individual specifics. For treatment that is already under way with OCD-affected children or youth, it may be prudent to skip ahead to modules that are most relevant at a given time.

Modules may be used selectively. Pacing of treatment is based upon clinical judgment, child and youth motivation and engagement, parent buy-in, session frequency and intensity, and between-session progress. Modules are intended to inspire confidence when treating pediatric OCD via ERP. We have intentionally included many case examples within modules to provide descriptions of how tools can be used selectively based upon clinical judgment.

Each module focuses on a specific OCD treatment-related topic, with suggestions on how to present this information to families, and selected pearls of wisdom accumulated by the authors. Reproducible parent and child/youth worksheets and handouts accompany each module. (See the box at the end of the table of contents.) Anecdotally, treatment approaches that are primarily behavioral in nature tend to result in the best outcomes for children and youth with OCD. Although some cognitive strategies have been included in the modules (e.g., *bossing back the OCD bully; coping cards*), the emphasis of "OCD Is Not the Boss of Me" is focused on ERP activities. The use of cognitive approaches that focus on recognizing faulty cognitions can leave the patient stuck in arguments about the "What ifs" (e.g., "What if I get HIV?" "What if I go to hell?" "What if I left the stove on?"). This is particularly the case if the clinician's emphasis is on attempting to challenge or change the content of the obsessions (e.g., "There's a very low chance that I left the stove on"). OCD is associated with poor tolerance of uncertainty (Hezel, Stewart, McNally, & Riemann, 2019). No outcome can be guaranteed with 100% certainty, so discussions around the likelihood of an outcome can leave children and youth focused on the 0.00001% chance of something bad happening to them. In addition, studies consistently demonstrate that exposure is the key element in overcoming anxiety, including OCD.

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