Table of Contents

Acknowledgments vii

Introduction 1

Chapter 1 Is It OCD? 3

Chapter 2 Understanding Your Child's Experience 11

Chapter 3 The Impact of OCD 23

Chapter 4 The Treatment of OCD 29

Chapter 5 Getting Help: Finding the Right Therapist 57

Chapter 6 Supporting Your Child's Treatment 65

Chapter 7 Case Examples: Bringing It All Together 79

Chapter 8 What to Expect on the Road Ahead 133

Chapter 9 Stress Management 139

Resources 145

References 153

About the Author 157

Introduction

Welcome to *Parenting Kids With OCD*! If your child or teen has been diagnosed with obsessive-compulsive disorder (OCD), or you suspect your child has it, then this is the book for you. I wrote this book in a straightforward manner, with the goal that after reading it, you will have gained a comprehensive understanding of OCD, its symptoms, types, how it presents in children, and what effective treatment looks like. You will learn the specifics of how it is best treated, and how to best support your child as she works toward overcoming the disorder. Everything I explain is based on cognitive-behavioral therapy (CBT), which is the most empirically supported approach to understanding and treating OCD.

As a specialist in anxiety disorders and OCD, I know firsthand the intensity that is involved in parenting a child with OCD and how it can affect your every move. *With OCD, family accommodation is the rule, rather than the exception, and the more accommodations a family makes, the more stressed that family is and the worse the child's OCD gets.* Higher levels of accommodation are linked with a worsening of symptoms. For this reason, I have included clear recommendations for how to gradually stop accommodating and what you can do instead. By being sensitive and warm, yet firm and consistent, you will develop a better way of responding to your child's OCD, which will benefit everyone enormously.

You will learn about how to find the right treatment for your child, and strategies that you can use at home and at school. We will go through many case examples to illustrate the different types of OCD and to better understand the course of treatment. We will also discuss

when more intensive treatment options should be considered and what to expect in the future.

Because stress exacerbates OCD symptoms in children, we will devote some attention to stress management for your child and for you as well, as it tends to be a parallel experience. Finally, I've included a list of resources and helpful organizations, as well as additional readings in the Resources section at the end.

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Chapter 1

Is It OCD?

Obsessive-compulsive disorder (OCD) has been identified and classified as a disorder since the very late 1800s. Beginning in the mid-1960s, behavioral approaches showed great promise for treatment, and by the 1980s, they evolved into cognitive-behavioral therapy (CBT), specifically exposure/response prevention (E/RP), which is currently used with great success in both the understanding and treatment of the disorder. By now, most cases of OCD are very treatable, and it is essential to have hope about your child's prognosis and his or her ability to succeed on the path toward improvement. This book is based on the principles of CBT, and my goal is for you to gain a thorough understanding that can then inform you when guiding your child toward improvement. Knowing the specifics of CBT will also help ensure that the treatment your child receives is both comprehensive and consistent with the approach.

Formally included in the category of anxiety disorders in the previous version of the Diagnostic and Statistical Manual of Mental Disorders (DSM; the bible for mental health practitioners that includes the criteria for all mental health disorders), OCD has become its own category called *Obsessive Compulsive & Related Disorders* (OCRD) in the current version, the DSM-V. This is due to the fact that OCD, unlike the other anxiety disorders, is linked with a host of other disorders, including body dysmorphic disorder (BDD), hoarding disorder, trichotillomania (hair pulling disorder), and excoriation (skin-picking) disorder, and that not all individuals with OCD actu-

ally experience anxiety. Regardless of the new categorization, most kids with OCD are incredibly anxious about their OCD and, often, anxious in general.

OCD affects 1%–3% of children and adolescents; at least 1 in 200 children and teens in the U.S. have OCD (American Psychiatric Association [APA], 2013; Ruscio, Stein, Chiu, & Kessler, 2010). Although OCD can appear at any time during childhood or adulthood, it typically starts between the ages of 10–12 or during late adolescence/young adulthood (Greist & Baudhuin, n.d.). In order to meet the criteria for OCD, your child must have either *obsessions* or *compulsions* (although most children have both) that cause an interference or impairment in his or her life. Obsessions are persistent unwanted or intrusive thoughts, urges, or images that the person cannot ignore or suppress. For most people, the obsessions cause anxiety and, often, intense fear. Compulsions are repetitive behaviors, rituals, or mental actions that are usually performed in response to the obsessions:

> The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviors or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive. (APA, 2013, p. 237)

The obsessions and compulsions must be time-consuming (take an hour or more a day) or they need to cause a significant impairment in the child's life (in academic, social, or other important areas of functioning). It is not necessary for an individual to have insight into the obsessions and compulsions (meaning that they don't have to be considered to be excessive or unreasonable to the child); however, most children find the obsessions and/or compulsions distressing and unpleasant.

Common types of obsessions include:

- ✧ contamination,
- ✧ repetitive doubting,
- ✧ desire for certainty,
- ✧ symmetry,

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- ✧ "just feels right,"
- ✧ scrupulosity,
- ✧ unwanted sexual thoughts,
- ✧ losing control or doing harm, and
- ✧ indecisiveness.

Common types of compulsions include:

- ✧ washing/cleaning,
- ✧ checking,
- ✧ needing to ask/tell/confess,
- ✧ counting,
- ✧ ordering/arranging,
- ✧ repeating actions,
- ✧ waiting until or doing it over until it "feels right,"
- ✧ praying, and
- ✧ asking for reassurance.

In addition to the common types of obsessions and compulsions, there are types of OCD beliefs that define the person's experience with OCD. These include:

- ✧ **Overimportance of thoughts:** Thoughts can be experienced as powerful as action or truth. Often, the child will question himself, doubting who he is and believing the faulty and unwanted OCD thoughts reflect his true intentions. He will believe that having a thought about something bad happening means it will happen (these are called *fusion* thoughts, which are discussed further in Chapter 4).
- ✧ **Desire for certainty:** Wanting to know for absolute sure that something did or did not happen. Being totally certain is associated with safety, and anything short of that is typically considered risky. This thinking pattern is often at the root of checking and rechecking and repetitive questioning behavior. The persistent doubting results from not feeling certain that something was completed.
- ✧ **Overestimation of danger:** There is a magnification of the world as being dangerous and an exaggerated sense that some-

thing bad will happen or go wrong. There is an unrealistic belief that factually nondangerous behaviors could result in catastrophic outcomes; for example, the child may believe that she can contract a disease like cancer or HIV from actions such as touching a surface or being around someone who is bleeding. The child feels that there are things that need to be done in order to prevent harm, and the rituals can typically reflect extreme avoidance.

- **Overresponsibility:** The child believes that it is his responsibility to ensure that something bad doesn't happen or that others don't get hurt. Often, the rituals will involve excessive checking and taking preventative measures. For example, the child may take it upon himself to check the house for fire risks every time before leaving. Making mistakes can be perceived as a threat to one's safety, as the person feels (on a sort of karmic-level) that he will be to blame for hurting someone or getting someone sick, or if he did not take "ideal" measures to prevent illness or harm.
- **Perfectionism:** Not only does the child think it is possible to be perfect, but she also thinks something needs to be perfect in order to count. Often the child will do something and redo it many times in efforts to make it perfect. There can be an excessive concern about needing to know information, a fear of losing or forgetting something important, and an inability to delegate tasks or trust others.
- **Rigid/Moral thinking:** This inflexible style of thinking assumes that there exists a fundamental "right" and "wrong" in life. If something is done that could be considered wrong, the person feels he will be at risk for punishment.
- **Religious scrupulosity:** Feeling like they have sinned when no sinning has occurred. It is similar to overresponsibility, as the person feels a sense of responsibility if he or she puts someone "at risk" by not taking preventative measures, yet the responsibility is rooted in his or her worth and/or approval from God: "The French label the emotional condition which is part of scrupulosity 'the doubting disease.' This describes

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well the dilemma of the scrupulous. They feel uncertain about religious experiences and do not find reassurance through the normal means available to them" (Ciarrocchi, 1995, p. 5). A person can have scrupulosity without having OCD, but we will focus on it when it occurs as the main theme or type in OCD. In *The Doubting Disease* (Ciarrocchi, 1995), the author explained that there are several possible themes of scrupulosity: honesty, blasphemy (against God), cooperation in sin, sexual ideas (e.g., worrying about being lesbian or gay or being a cheater), and charity (e.g., where the person questions her goodness when it comes to serving others).

- **Sexual Obsessions:** This can be an extension of religious scrupulosity, or the sexual obsessions can occur outside of any scrupulosity. They can include preoccupation with sexual thoughts, sexual orientation, mislabeling normal sexual thoughts as perversion, thoughts about molesting other children or being a pedophile, or having sexual contact with someone inappropriate, such as a teacher or friend's parent. Usually occurring in older children or teens, these thoughts create a great deal of distress, including guilt, shame, and embarrassment.

Although the causes of OCD are not known, it does tend to run in families, implying a genetic component, although genes are not fully responsible for causing it (Greist & Baudhuin, n.d.). Sometimes, it can be associated with strep infections. PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections) is caused by the body's response to strep infection, not the actual infection; therefore, it seems to be a faulty reaction of the immune system. A child can be diagnosed with PANDAS when OCD symptoms suddenly appear (acute onset) in a dramatic way, almost like the child developed OCD overnight. Often this diagnosis follows multiple strep infections. However, PANDAS has been expanded to Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) as studies showed that PANDAS symptoms did not always begin after strep infection. Typically, OCD has a more gradual presentation; for example, a child

may begin to express some extra concern about germs, ask a lot of contamination-themed questions, then start to wash a little extra, then show some avoidance of doorknobs and public restrooms or of eating food without washing her hands first, and then over months or years, it becomes more severe and time-consuming.

Children who receive the PANDAS diagnosis still need to undergo traditional CBT treatment for the OCD; however, the reason it is relevant to consider a PANDAS/PANS diagnosis is that additional treatment and pharmacological interventions (such as longer term antibiotic treatment, or in more severe cases, plasmapheresis, steroids, or intravenous immunoglobulin, IVIG) may be helpful. PANDAS is still being investigated, and there is some disagreement among clinicians in terms of its validity. From my standpoint, I am primarily concerned with the resolution of symptoms; therefore, when a child comes to see me for OCD treatment, regardless of if a PANDAS diagnosis has been made, I follow the same course of CBT treatment and get the same positive outcomes as those who come without it. Usually children are referred to me after receiving a PANDAS/PANS diagnosis, but sometimes I suspect a case of OCD may be rooted in PANDAS/PANS, and when this occurs, I will follow along with my typical treatment, but if after 3–4 months there is not enough improvement, I will refer out to specific pediatric neurologists who are careful not to overdiagnose the condition.

Sometimes obsessions and/or compulsions, or what may appear to be either, are symptoms of another disorder, so it is necessary to make a "differential diagnosis," which means that a diagnosis must involve consideration of what else it could be. Therefore, other diagnoses need to be ruled out. Body dysmorphic disorder (BDD) occurs when there is a preoccupation with one or more aspects of one's appearance that he or she perceives to be flawed; while the person is consumed with thoughts about it for at least an hour a day, the obsessions and compulsions are limited to a focus on physical appearance. With hoarding disorder, the symptoms are centered on difficulty with getting rid of possessions; there can be a compulsion to accumulate and save items, yet the focus is concerning the items (and refusing to part with them). It is also possible that the obsessive ruminations (recurring worries) are bet-

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ter explained by generalized anxiety disorder (GAD), which is when there is hard-to-control anxiety and worry lasting for at least 6 months that, again, causes an impairment in the person's life. For GAD, the person must have symptoms such as feeling restlessness, being easily fatigued, irritability, difficulty concentrating, muscle tension, and so on. One can also have GAD with obsessive features without meeting the full criteria for OCD. Other anxiety disorders, such as social phobia and separation anxiety disorder, may also need to be considered, as the repetitive fears about being judged negatively or about something bad happening to a loved one can resemble obsessions. Similarly, someone with major depression may ruminate in a way that appears obsessive (e.g., guilty ruminations); however, the thoughts are more reflective of the person's mood (mood-congruent) and not necessarily experienced as distressing. Also with depression, there tend to not be any compulsions.

Perfectionism may or may not be OCD. In some cases, perfectionism is its own problem, having little to do with OCD. Other times, it is part of the OCD, specifically the "just feels right" type. There can be an obsessive preoccupation with symmetry or order, which manifests like perfectionism, but the behavior associated with this preoccupation is really a compulsion (ritual). Finally, eating disorders can often present as OCD (e.g., ritualized eating behavior, avoidance of certain foods) but are limited to concerns about food and weight. When the disturbance of the obsessions and/or compulsions is better explained by one of these other disorders, then a different diagnosis is made. (This book focuses only on OCD; refer to http://www.iocdf.org for resources on these other topics.)

Alternatively, a child can meet the criteria for OCD and another disorder at the same time; this is called *comorbidity*, as both disorders are co-occurring in the child. For example, it is not uncommon for a child who has OCD to also have generalized anxiety disorder or social anxiety disorder. About 30% of children with OCD will also have an anxiety disorder, and often this is separation anxiety disorder (Boileau, 2011). Thirty-nine percent of children and 62% of adolescents will have symptoms of major depression at some point in the course of their OCD (Boileau, 2011). Tourette's disorder occurs in 25% of children