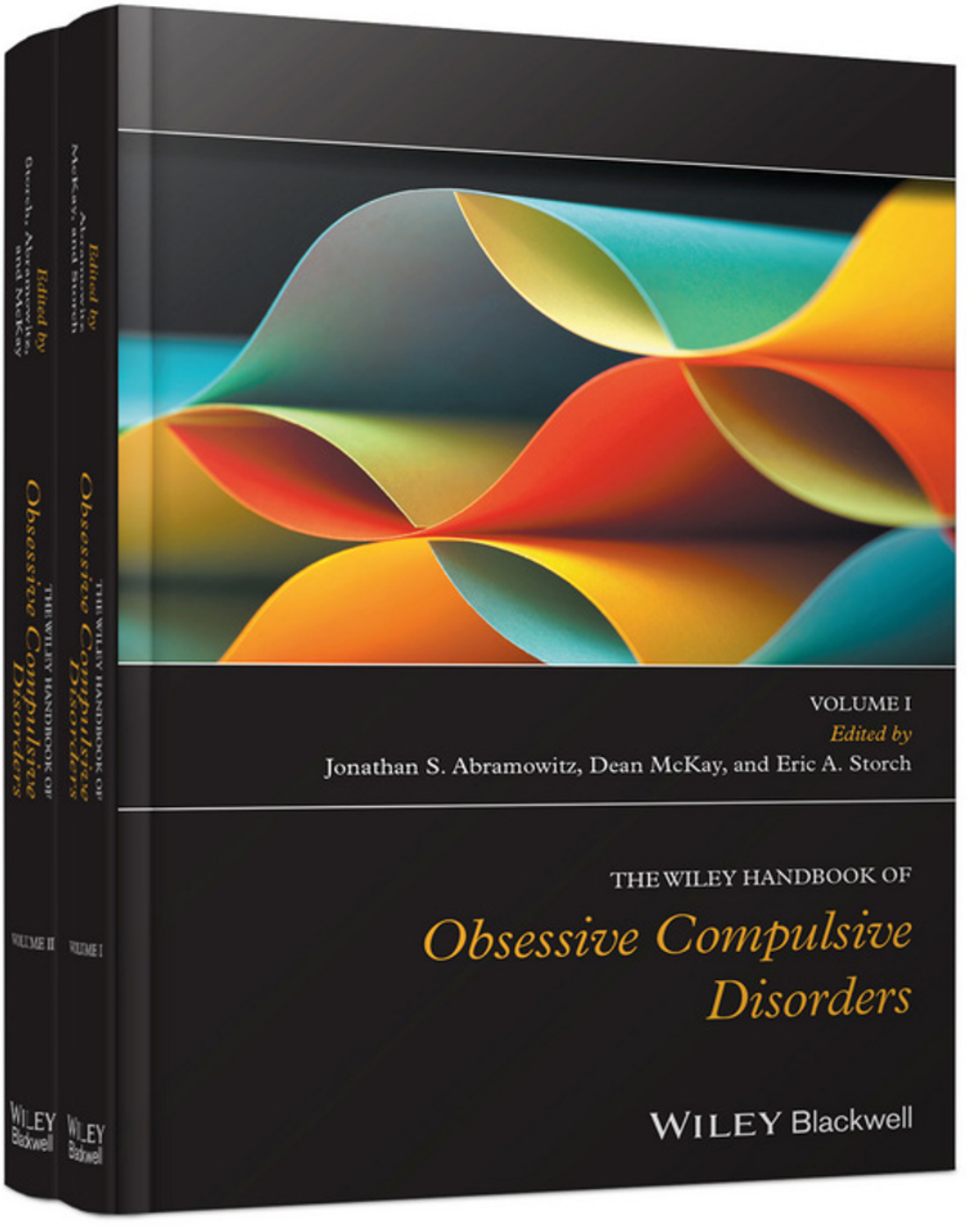
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Volume I

Edited by

Jonathan S. Abramowitz, Dean McKay, and Eric A. Storch

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Obsessive-Compulsive and Related Disorders

Where Have We Been?

Dean McKay, Jonathan S. Abramowitz, and Eric A. Storch

Obsessive compulsive disorder (OCD) was once considered a very rare and untreatable condition (Kringlen, 1965). However, in the past fifty years changes in how the condition is defined and understood has led to the identification of a broad swath of symptoms and associated features that suggest the disorder is fairly common, afflicting up to approximately 1.2%–3% of the population (i.e., Ruscio, Stein, Chiu, & Kessler, 2010; Yuki, Meinlschmidt, Gloster, & Lieb, 2012). Further, research has shown that those with OCD have high rates of disability and occupational and social role dysfunction (Markarian et al., 2010). When the prevalence and functional impairment are considered together with the anxiety and distress that individuals with this condition experience, one recognizes that OCD represents a significant public health concern.

Given the frequency of OCD in the general population, the need to develop effective interventions became clear. At the present time, practice guidelines for OCD treatment emphasize two broad approaches: cognitive-behavior therapy (CBT), particularly exposure with response prevention (ERP); and/or cognitive interventions aimed at specific obsessional belief structures, or serotonin reuptake inhibitor (SRI) medications. Treatment employing CBT is presently associated with large effect sizes (McKay et al., 2015) for both ERP and cognitive therapy tailored to the condition. Relative to psychotherapeutic interventions, SRI medications have somewhat lower effect sizes for symptom relief (Fineberg et al., 2015). These two treatment approaches, broadly speaking, have improved the lives of countless OCD sufferers.

Unfortunately, however, the outlook is not necessarily so rosy for all people with OCD. First, a significant minority fail to respond to the available treatments, with estimates of non-response as high as 30%. Research has suggested that factors that contribute to non-response include high levels of scrupulosity; overvalued ideas regarding the accuracy of obsessions and/or necessity of compulsions; comorbid psychopathology, such as depression or trauma; emotional states other than anxiety as motivator of avoidance; and noncompliance with the demands of treatment. Second, there are additional factors that can contribute to poor outcome that include poor delivery or implementation of CBT, erroneous functional assessment of primary

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symptoms, and inadequate attention to cultural factors (reviewed in McKay, Arocho, & Brand, 2014). Third, it has also been shown that some specific symptoms of the condition respond better to treatment than others (i.e., checking versus symmetry/ordering; Abramowitz, Franklin, Schwartz, & Furr, 2003). These are significant issues to reckon with in the delivery of care for OCD.

The aim of Volume 1 of this two-volume set is to provide practitioners and researchers with a comprehensive resource for conceptualizing, assessing, and treating the full range of obsessive-compulsive symptoms. While the DSM-5 definition of OCD captures a broad array of symptoms, clinicians and researchers have observed that patients with specific types of symptoms are differentially responsive to available treatments. This differential treatment response has led researchers and clinicians to propose that clinically important subtypes of OCD exist. In turn, these proposals have prompted the development of theoretical mini-models for various presentations of the condition (e.g., contamination, scrupulosity), each with their own assessment and treatment implications. Given the impressive heterogeneity of the disorder, and the need to understand specific symptom subtypes in the unique manner of their manifestation, it is our expectation that the chapters in Volume 1 will be an invaluable resource for providing effective care to the full range of OCD sufferers.

Once it is appreciated how obsessional experiences manifest, it is tempting to examine other forms of psychopathology to determine what, if any, characteristics might resemble OCD. For more than two decades, efforts to conceptualize a range of psychopathology as part of a putative obsessive-compulsive spectrum have been underway (i.e., Hollander, 1993). The list of candidate disorders for this spectrum has varied, with some writing suggesting a large proportion of DSM-defined disorders fitting in the category, to narrower conceptualizations with a much more conservative set of so-called "spectrum" conditions (Hollander, Braun, & Simeon, 2008; Storch, Abramowitz, & Goodman, 2008).

The theoretical, conceptual, and clinical justifications for including or excluding certain conditions from the obsessive-compulsive spectrum has varied, with some taking a pragmatic model approach via commonalities in phenomenology and response to comparable treatments (i.e., Fineberg, Saxena, Zohar, & Craig, 2011) to a more theory-driven model premised on a breakdown in behavioral inhibition (Hollander & Rosen, 2000). The former approach derives from several sources. First, individuals with a range of other psychopathology report intrusive images and seemingly "compulsive" behavior germane to their diagnosis. Therefore, an individual with hoarding could be said to have "obsessions" regarding opportunities to gather new material goods that would interfere with her or his cognitive processing of other information. Similarly, someone with body dysmorphic disorder (BDD) "compulsively" checks their appearance to reduce distress. Second, individuals with some other forms of psychopathology respond to treatments that are effective for OCD. Research suggests that SRI medication can be helpful in alleviating body image concerns associated with BDD (Phillips, 2004). Third, it has been suggested that putative obsessive-compulsive spectrum disorders share clinical and demographic characteristics, such as family history, comorbidity, and course of illness. The impetus from this pragmatic perspective provides an intuitive rationale for a spectrum of obsessive-compulsive disorders, since this conceptualization could serve to streamline the way in which clinicians develop treatments for a much larger range of clientele. Notably, others have questioned this approach on the basis of its conceptual foundation and lack of definitive data (e.g., Abramowitz & Jacoby, 2015; Storch et al., 2008).

The latter approach, a breakdown in behavioral inhibition, derives from a brain-based model of executive functioning related to control over actions. A theory-derived model would also have wide appeal, since it would permit researchers and clinicians to conceptualize a wide range of conditions within a single theoretical model, and again have the net effect of streamlining treatment. Advocates for this approach, now referred to as the obsessive-compulsive related disorders (OCRDs), cite these factors in support of the recent addition of this category to the Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association, 2013). Given the degree that there are disorders conceptualized in this manner, a journal has been launched devoted entirely to this category of disorders (*Journal of Obsessive-Compulsive and Related Disorders*). While the research on shared and unique features that other psychopathology may have with OCD continues, the conditions that are formally part of this category in the DSM-5 are as follows: OCD, Hoarding, Excoriation Disorder, Trichotillomania, and Body Dysmorphic Disorder. While there have been a number of virtues raised regarding this model, there have also been a number of critiques that range from limited support for the conceptualization in the empirical research (Abramowitz et al., 2009; McKay, Abramowitz, & Taylor, 2008) to faulty conceptualization of the research itself (McKay & Neziroglu, 2009).

In light of the heterogeneity of OCD, it should not come as a surprise that the disorders that form the OCRD are likewise complex and varied. In conceptualizing and developing this two-volume set, we determined that readers would be best served by chapters that cover not only the disorders that form the newly developed OCRD class of conditions in DSM-5, but a wider range of conditions that have, at one point or another, been characterized in the research as a possible member of this category. Accordingly, this includes health anxiety (and formerly Hypochondriasis) as well as Tourette Syndrome. It also led to the identification of problems commonly associated with OCD that may also play a role in putative related disorders. To cite one example, sensory intolerance is a problem that has been gaining increased recognition among practitioners and researchers. It is also a problem observed in some conditions associated with OCD, such as Tourette Syndrome.

As a result of this broad-reaching categorization for the OCRD, the chapters in Volume 2 cover a diverse array of conditions, associated treatments, and interventions for ancillary problems observed in OCD as well as the OCRD, such as the aforementioned sensory intolerance, problems in incompleteness and harm avoidance, and remote treatment delivery. It is hoped that readers will come away with a sense of optimism that the treatment needs of a very large segment of sufferers can be addressed with the range of material available in these two volumes. It is likewise the wish of the editors that these texts will further stimulate discussion and scholarship about the nature and treatment of these conditions.

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1

Description and Prevalence of OCD in Children and Adolescents

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Early case descriptions of children and adolescents with symptoms of what we now know as obsessive-compulsive disorder (OCD) were believed to be extremely rare, with little knowledge of prevalence, course, and effective treatment. The first description of childhood OCD is thought to have been described by Pierre Janet in 1903, when he presented the cases of two children aged 5 and 11 years. When describing the 5-year-old, Janet (1903) penned "no reassuring satisfies: the patient must be forever verifying his honesty, cleanliness, sanity, perceptions, and what he did last." In another early description of OCD, Kanner (1962) described children with "constricted" premorbid personalities, having been raised with an "overdose of parental perfectionism."

The changing landscape of definitions and knowledge of OCD is most evident in the evolution of diagnostic criteria, with revisions to criterion reflecting advancement in science and knowledge about this condition. The release of the *Diagnostic and Statistics Manual,* third edition (DSM-III) (American Psychiatric Association [APA], 1980) was a significant shift that saw diagnostic criteria for mental disorders described in more categorical terms, which attempted to remove all evidence of earlier psychodynamic explanations for disorders and, instead, reframed diagnostic categories according to symptom clusters or patterns (Clegg, 2012). It was after the release of the DSM-III with clear categorical descriptions of OCD, that research particularly focused on children and adolescents came to the forefront. The DSM-III was not long followed by the release of the DSM-III-R (APA, 1987), with the updated version being a reflection of the most current knowledge derived from evidence-based research. In the case of OCD, the DSM-III stated the disorder was rare in the general population; this was updated in the revised edition to reflect the recent community studies examining prevalence, suggesting mild forms of the disorder may be relatively common. Evolving knowledge from clinical trials (e.g., POTS, 2004), as well as neurobiological and genetic research (see Pauls, Abramovitch, Rauch, & Geller, 2014), has informed the most current description of the disorder in the latest revision of the

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DSM (APA, 2013). In the DSM-5, OCD is characterized by the presence of obsessions, defined as "recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress"; and/or compulsions, defined as "repetitive behaviors or mental acts that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly" (APA, 2013: 237).

With the recent release of the DSM-5, it is timely to review the description and prevalence of this disorder, investigating the changes to diagnostic criteria, as well as subtypes and specifiers, that have improved diagnostic validity and clinical utility. OCD is considered a prominent mental health condition affecting children and adolescents, as well as adults. This chapter presents a description of OCD in children and adolescence, highlighting advances in knowledge of OCD in recent decades and the implications this has had on the structure of diagnosis, symptomology, comorbidities, prevalence, and course.

Diagnosis

There are two predominant diagnostic manuals used for describing psychiatric conditions, the International Classification of Diseases (ICD) and the Diagnostic and Statistics Manual (DSM). The ICD is a core function of the World Health Organization (WHO), a global health agency of the United Nations, and represents an international manual that defines diseases, disorders, injuries, and other related health conditions. The current version, the ICD-10, was endorsed in 1990 and is currently under review with the eleventh version, ICD-11, expected to be released in 2015.

The DSM, now in its fifth revision, is the standard classification of mental disorders used in the United States, and contains a listing of diagnostic criteria for every psychiatric disorder recognized by the US healthcare system. Both the ICD-10 and DSM-5 give diagnostic criteria for OCD, which differ slightly (see Table 1.1).

An important shift in classification of OCD occurred in the DSM-5 revision (APA, 2013), whereby OCD was removed from the anxiety disorders section and placed in the newly established Obsessive-Compulsive and Related Disorders (OCRD) category. The newly created category consists of OCD and other related disorders, including body dysmorphic disorder (BDD), trichotillomania (hair-pulling disorder), hoarding disorder, excoriation (skin-picking), substance/medication-induced obsessive-compulsive and related disorder, obsessive-compulsive and related disorder due to another medical condition, other specified obsessive-compulsive and related disorder, and unspecified obsessive-compulsive and related disorder. This grouping does not imply that people with obsessive-compulsive disorder are non-anxious; but rather reflects research findings that the disorder has more similarity to other obsessive-compulsive-related disorders than to anxiety disorders (Abramowitz, Taylor, & McKay, 2009). The cluster of disorders comprising the OCRD chapter share core features such as an obsessive preoccupation and repetitive behaviors. Further, the OCRDs also overlap in their phenomenology, comorbidity, neurotransmitter/peptide systems, neurocircuitry, family history and genetic factors, and treatment response (Hollender, Braun, & Simeon, 2008).

Table 1.1 Diagnostic criteria for Obsessive-Compulsive Disorder based on ICD-10 and DSM-5

Criteria	*ICD-10*	*DSM-5*
Symptoms	Either obsessions or compulsions (or both)	Presence of obsessions, compulsions, or both
Definition of symptoms	Obsessions (thoughts, ideas, or images) and compulsions (acts) share the following features, all of which must be present: • acknowledged as originating in the mind of the patient; • they are repetitive and unpleasant, and at least one obsession or compulsion must be present that is acknowledged as excessive or unreasonable; • the subject tries to resist them and at least one obsession or compulsion must be present that is unsuccessfully resisted; • carrying out the obsessive thought or compulsive act is not pleasurable.	Obsessions are recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress. Compulsions are repetitive behaviors (e.g., hand-washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.
Duration	Present on most days for a period of at least two weeks.	The obsessions or compulsions are time-consuming (e.g., take more than 1 hour/day).
Impact on functioning	The obsessions or compulsions cause distress or interfere with the subject's social or individual functioning, usually by wasting time.	Symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
Exclusionary criteria	Not due to other mental disorders.	Symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition. The disturbance is not better explained by the symptoms of another mental disorder.
Specifiers	• Predominantly obsessional thoughts and ruminations. • Predominantly compulsive acts. • Mixed obsessional thoughts and acts. • Other obsessive-compulsive disorders. • Obsessive-compulsive disorder, unspecified.	Insight specifier: • with good or fair insight; • with poor insight; • with absent insight/delusional beliefs; Tic subtype specifier: • the individual has a current or past history of a tic disorder.

As it is widely accepted that these disorders are often under-recognized, undertreated, and understudied, the DSM-5 approach to categorizing OCRDs may help clinicians better identify and treat individuals suffering from these disorders (Hollender et al., 2008). Moreover, given the high degree of comorbidity observed between the OCRDs, clinicians should routinely assess children and adolescents for these related disorders if one or more conditions from this cluster has already been diagnosed (Van Ameringen, Patterson, & Simpson, 2014). While these disorders share similarities that conceptually guided the decision to group them together, there are also important differences among them that distinguish distinct diagnoses and call for unique approaches to cognitive-behavior therapy (CBT).

The revision of the "insight" criterion in the DSM-5 reflects the substantial advancement in research of the disorder since the publication of the DSM-IV-TR (APA, 2000). The DSM-IV-TR criteria requiring that individuals realize that their obsessions and compulsions are unreasonable or excessive has been removed in the DSM-5, and the specifier *with poor insight* added allowing for a more dimensional approach to record insight: w*ith good or fair insight*, *with poor insight*, or *with absent insight/delusional beliefs*. This is a reflection of empirical evidence that insight falls on a continuum, with many individuals not recognizing the excessive and unreasonable nature of their obsessive or compulsive symptoms (Storch et al., 2014). It is known that children tend to have less insight regarding their illness than their adult counterparts (Foa & Kozak, 1995), which has implications for assessment, treatment provision, and treatment outcome (Storch et al., 2014). Storch and colleagues explain that youth with poor insight may not recognize their symptoms as problematic and therefore often resist engaging in the treatment process due to limited motivation or disruptiveness contributing to negative treatment outcomes. Moreover, insight has been associated with a number of clinical characteristics, including symptom severity, preponderance of compulsions, illness chronicity, limited patient resistance against and presumably control of symptoms, early symptom onset, and a positive family history of OCD (Storch et al., 2014).

The DSM-5 also introduces an additional specifier if the condition is tic-related, whereby the individual has a current or past history of a tic disorder. Epidemiological research has reported a high comorbidity between OCD and Tourette's Syndrome/tic disorders, estimated to be between 26% and 59% (Eichstedt & Arnold, 2001). A tic is described by the DSM-5 (2013) as a sudden, rapid, recurrent, nonrhythmic motor movement or vocalization. Compared with patients with OCD alone, patients with comorbid tics usually present with an earlier age of onset and are more frequently males, suggesting there are phenotypic differences in OCD patients with Tourette's Syndrome/tic disorders (Diniz et al., 2006; Leckman et al., 1994a; Leonard et al., 1992). Moreover, tic-related OCD presentations are likely to be accompanied by presence of antecedent sensory phenomena (Leckman et al., 1994b; Miguel et al., 2006; Prado et al., 2008). Leckman and colleagues (2010) describe sensory phenomena, including localized tactile and muscle–skeletal sensations; "just-right" perceptions associated with visual, tactile, or auditory stimuli; feelings of "incompleteness"; and an "urge." Of clinical importance, a poorer treatment response with selective serotonin re-uptake inhibitor (SSRI) monotherapy in children and adolescents with OCD and comorbid tics (versus those without tics) was reported in a prospective study of children (March et al., 2007). Consistent with Geller and colleagues (2003a), the use of an SSRI was superior to placebo only in patients without tics (March et al.,

2007). Therefore, March and colleagues recommended that children and adolescents with OCD, as well as a comorbid tic disorder, should begin treatment with CBT alone or the combination of CBT plus an SSRI.

Symptomology

OCD in childhood and adolescence is a heterogeneous condition; with most children and youth presenting with a wide constellation of obsessional concerns and compulsive behaviors. Due to symptoms varying widely from patient to patient, the diagnostic manuals, namely, the International Classification of Diseases (ICD) (World Health Organization, 1992) and the DSM (APA, 2013), give general definitions of obsessions and compulsions that may be present in conjunction with, or in the absence of, the other symptoms. Childhood OCD can be episodic in presentation and is frequently reactive to stress, whereby children and adolescents experience acute symptom exacerbations during times of psychosocial challenge, such as the start of school year or moving to a new home (Piacentini & Bergman, 2000; Swedo, Rapoport, Leonard, Lenane, & Cheslow, 1989).

OCD is indeed a complex and debilitating disorder, with most young people endorsing numerous symptoms at any one point in time (Geller & March, 2012). Symptoms in children and adolescents may comprise compulsive washing, checking, repeating, counting, ordering, hoarding, magical thinking or rituals involving other people, as well as obsessions regarding contamination, aggressive thoughts, hoarding, somatic, religious, superstitious and sexual beliefs (Scahill, Riddle, & McSwiggin-Hardin, 1997). In children and youth, OCD presents in widely diverse forms as can be seen from case illustrations in Table 1.2, which describes a variety of cases included in our current clinical trials at Griffith University.

Recently, research has begun to investigate if differences exist in symptomology seen in younger versus older children. In a recent clinical study, Selles, Storch, and Lewin (2014) investigated the presentation of obsessive-compulsive symptoms in younger children aged 3–9 years old versus older children aged 10–18 years. The younger group were described as having less resistance and control of compulsions, and exhibited significantly poorer insight, increased incidence of hoarding compulsions, higher rates of comorbid attention deficit/hyperactivity disorder, disruptive behavior, and parent-rated anxiety. Older youth demonstrated stronger intensity of obsessive and compulsive symptoms, exhibited increased occurrence of comorbid depression, and an increased occurrence of sexual, magical thinking, and somatic obsessions, as well as, checking, counting and magical thinking compulsions.

Researchers and clinicians have hypothesized that patients with specific types of symptoms and comorbid presentations may represent different subtypes of the disorder, associated with diverse etiologies and response to treatments. The heterogeneous array of symptoms observed in OCD, coupled with the disparity in response to treatment, has prompted the development of methods for identifying subtypes of OCD to allow for systematic evaluation of possible differences in treatment response or disorder etiology associated with these different subtypes (McKay et al., 2004). In the adult literature, researchers have looked to the Yale–Brown Obsessive Compulsive Scale (Y-BOCS) (Goodman et al., 1989) due to the comprehensive checklist of over

Table 1.2 Case illustrations of children and adolescents with Obsessive-Compulsive Disorder

Name	*CY-BOCS score*	*Primary obsession*	*Primary compulsion/avoidance*	*Other OC symptoms*	*Diagnostic profile (ADIS-IV-P CSR rating)*
Grace 15 yr	32	Aggressive/sexual: fear that she is a pedophile and will make sexual advances toward young children.	Would avoid parks, playgrounds, the beach, school play time, so that she would not come into contact with young children.	• Contamination fears • Just right: school work	OCD (6) Specific phobia of spiders (4) GAD (4)
Zoe 12 yr	30	Not just right: fear of not being good enough, failing, being "wrong."	Repeating compulsions: will rip out pages from books if they are not perfect. Slowness with handwriting. Will rub out school work and re-write.	• Checking • Hoarding	OCD (5) BDD (4) GAD (4) Specific phobia vomiting (4)
Liam 16 yr	38	Contamination: fear of contracting AIDS or illness through bodily fluids and spreading contamination to his family.	Washing and cleaning: clean toilet and bathroom for up to 8 hours day. Excessive use of chemical cleaning products and hand-washing.	• Checking • Magical beliefs • Rituals involving others • Hoarding	OCD (7) ODD (4)
Ryan 10 yr	27	Aggressive/harm: fears taps will leak and flood the house, as well as power points and light switches will cause a fire.	Checks the taps, light switches, and power points are turned off up to 30 times/day	• Arranging/ symmetry • Rituals involving others • Doubting	OCD (5) Social phobia (5) GAD (4) Specific phobias: high places(4), planes (4), and elevators (4)

Note: CY-BOCS = Children's Yale–Brown Obsessive Compulsive Scale (Scahill et al., 1997); Primary obsessions/compulsions defined as those OC symptoms causing highest level of functional impairment; CY-BOCS score range = 0–7 subclinical, 8–15 mild, 16–23 moderate, 24–31severe, 32–40 Extreme; ADIS-IV-P = Anxiety Disorders Interview Schedule for DSM-IV: Parent Version (Silverman & Albano, 1996); CSR = Clinician Severity Rating: based on clinician judgment, scored 0–8, with a score of 4 indicating a clinically significant diagnosis; GAD = Generalized Anxiety Disorder; BDD = Body Dysmorphic Disorder; ODD = Oppositional Defiant Disorder.

60 specific OCD symptoms organized into obsession and compulsion categories. Researchers have applied factor analysis to subtype symptom representations.

Adult studies have generally supported a four-factor model to explain OCD symptom clusters. For example, Albert and colleagues (2010) conducted a factor analysis on a sample of 329 adults (mean Y-BOCS score of 24.9) and yielded a four-factor solution accounting for 58% of the variance of the Y-BOCS data. The factors included (a) symmetry, (b) forbidden thoughts, (c) cleaning, and (d) hoarding, which are representative of the international literature (see Bloch, Landeros-Weisenberger, Rosario, Pittenger, & Leckman, 2008; Cullen et al., 2007; Leckman et al., 1997). This four-factor model has also been replicated in a small number of studies involving children using the Children's Yale–Brown Obsessive Compulsive Scale (CY-BOCS) (Scahill et al., 1997; see Delorme et al., 2006; Mataix-Cols, Nakatani, Micali, & Heyman, 2008; McKay et al., 2006; Stewart et al., 2007). Bloch and colleagues conducted a meta-analysis of child studies investigating the factor structure of the CY-BOCS. On the basis of four studies involving 679 participants, the authors reported the four-factor structure explained 81.7% of the heterogeneity in the clinical symptoms of childhood OCD. Symmetry obsessions and checking, repeating, ordering, and counting compulsions loaded highly on factor 1 (symmetry, 28.7%). Cleaning, contamination, and somatic obsessions loaded highly on factor 2 (cleaning, 19.9%). Hoarding obsessions and compulsions loaded highly on factor 3 (hoarding, 16.7%). Aggressive, sexual, and religious obsessions loaded highly on factor 4 (forbidden thoughts, 16.4%). When comparing the factor structure between adults and children, Bloch and colleagues reported that they were identical with the exception of two minor differences. The first of these differences, checking compulsions, loaded highest on the forbidden thoughts factor in adults and on the symmetry factor in children; and, second, the somatic obsessions loaded highest on the forbidden thoughts factor in adults and on the cleaning factor in children.

While the few child studies conducted to date have consistently supported a four-factor model, there is some variability across studies at an item level within each of the factors. The variability observed among symptoms within the factors possibly reflects a combination of the differences between samples and ambiguity of some CY-BOCS items used in assessing OCD symptomology (Stewart et al., 2007). Of particular consideration, in each of the CY-BOCS factor studies, several symptom domains items were associated with more than one factor. This suggests the possibility that in childhood, symptom dimensions are less well developed and discrete dimensions of symptoms in OCD is not evident until later in development, or only after the symptoms have been present for a longer period of time (McKay et al., 2006). These findings are consistent with both research and clinical observations of OCD during childhood and adolescence, whereby young people frequently present with a wide and diverse constellation of symptoms that frequently change over time.

Leckman, Bloch, and King (2009) proposed distinct subtypes within pediatric OCD offering potentially useful categorical distinctions that better capture the heterogeneity of the disorder. Subtypes included tic-related OCD, familial non-tic-related early onset OCD, and pediatric autoimmune neuropsychiatric disorders associated with streptococcal (PANDAS) infections. Tic-related OCD was defined as when tics are observed either in the proband or in one or more first-degree family members. This subtype generally shows a male predominance, as well as symptoms that correspond to symmetry, forbidden thoughts, and hoarding dimensions (Leckman

et al., 2009). In the case of familial OCD, higher than expected rates of anxiety and affective disorders are seen in early-onset cases and their first-degree family members. Moreover, children are likely to suffer with obsessional concerns about the safety of family members as well as contamination and compulsive washing compulsions. Finally, some susceptible individuals develop OC symptoms as a result of post-infectious autoimmune processes (Leckman et al., 2009). In recent times, an increase in evidence has pointed to immune-related causation in a minority of cases of childhood-onset OCD, most likely due to a Group A streptococcus (GAS) infection (Murphy et al., 2004). Despite interest and evidence for PANDAS, there are issues that preclude this as a formal OCD subtype in diagnostic terms due to concerns over reliability of the diagnosis, testing procedures, the use of antibiotics in treatment, and it seems that PANDAS can lead to a broader spectrum of developmental disorders in addition to just OCD (Thomsen, 2013).

In a novel study, Storch and colleagues (2008a) examined the extent to which symptom dimensions among youth with OCD were associated with CBT response in a sample of 92 children and adolescents aged 7–19 years, diagnosed with OCD. Symptom subtypes included symmetry/ordering, contamination/cleaning, sexual/religious obsessions, aggressive/checking, and hoarding symptoms. The majority of participants (76%) were rated as much improved or very much improved after 14 CBT sessions, supporting the guidelines that CBT should be recommended as the first-line treatment for youth with OCD, regardless of presenting symptoms (Geller & March, 2012). Overall, there was no difference in the response to CBT across pediatric OCD subtypes. However, participants with aggressive/checking symptoms at baseline showed a trend toward being more likely to respond to treatment than those who endorsed only nonaggressive/checking ($p = 0.06$). The authors hypothesized the reason patients with checking rituals and harm obsessions had a better response to CBT is the length of time between the onset of the obsession and the feared consequence is typically quite short. Drawing from operant conditioning theory, these symptoms may be more acquiescent to extinction with exposure and response prevention due to the close temporal connection between behavior (e.g., exposure) and punishment (e.g., feared consequence) (Storch et al., 2008a). Further understanding of treatment response profiles for specific presentations of OCD in youth may help to inform efforts to individualize treatment approaches based on symptom and subtype presentations, which may translate to improved treatment outcomes. However, beyond the psychopathology of dimensions and subtypes, there is ample evidence to suggest that to be effective, cognitive-behavioral treatment procedures indeed should be adjusted to each individual in order to address the specific symptom manifestations in OCD (McKay et al., 2004).

Comorbidity

It is widely understood that comorbid conditions are frequent in OCD, with the addition of the DSM specifier for tic-related OCD highlighting the important role comorbidity plays in understanding the nature of the unique presentation and the likely heterogeneity of treatment response. Comorbidity is indeed a serious consideration in pediatric OCD and has been reported to be as high as 86% in a recent

clinical sample (Farrell, Waters, Milliner, & Ollendick, 2012), with as many as 50–60% of youth experiencing two or more other mental disorders during their lifetime (Rasmussen & Eisen, 1990). Comorbid conditions heavily contribute to the debilitating nature of this disorder, the complexity in treating OCD patients, and why it is so often described as a complex psychiatric disorder (Farrell et al., 2012; Geller et al., 2003b; Masi et al., 2006; Sukhodolsky et al., 2005). The most common comorbid conditions of pediatric OCD include anxiety disorders, depression, tics and Tourette's Syndrome, attention deficit/hyperactivity disorders (ADHD), disruptive behavioral disorders, and pervasive developmental disorders (PDD) (Farrell et al., 2012). The frequency of these common comorbid disorders based on a selection of studies that have specifically investigated comorbidity in children and adolescents is presented in Table 1.3.

Certain comorbid disorders associated with OCD in youth (e.g., disruptive behavioral disorders, depression, attention deficit disorder) impact heavily upon the severity of a child's OCD, and have a negative effect on children's psychosocial functioning, and also response to treatment (Storch et al., 2008b; Storch, Lewin, DeNadai, & Murphy, 2010). Storch and colleagues (2008b) examined the impact of comorbidity in CBT response in a sample of youth with a primary diagnosis of OCD. In this study, it was found that having one or more comorbid conditions was associated with a poorer response to CBT outcome, and that the combined number of comorbid conditions was negatively related to outcome. Similar findings were found by Farrell and colleagues (2012) in a study of the effectiveness of group CBT for children and adolescents who presented with OCD and complex comorbid conditions. Comorbidity was not associated with poorer treatment outcomes at post-assessment; however, at 6-month follow-up outcomes were poorer for youth with multiple comorbid conditions and for those with attention deficit/hyperactivity disorder. Taken together, research indicates the presence of a comorbid externalizing disorder (i.e., attention deficit/hyperactivity disorder, oppositional defiant disorder (ODD), and conduct disorder) is associated with poorer treatment response and lower treatment remission rates (Garcia et al., 2010; Ginsburg, Newman Kingery, Drake, & Grados, 2008; Storch et al., 2008b).

Prevalence

Less than three decades ago, OCD was thought to be a rare condition in children, with limited literature available describing childhood OCD prevalence from retrospective reviews of child psychiatric samples (Flament et al., 1988). One of the first studies of reported prevalence found six cases of obsessive compulsive neurosis in a sample of more than 3,000 children admitted to a hospital or children's treatment facility, giving an estimated prevalence of 0.2% (Berman, 1942). In an early adult sample, Skoog (1965) described "obsessive neurosis" symptoms starting before the age of 19 in 15% of patients, recognizing OC symptoms as starting earlier than most other psychiatric problems of adulthood.

Judd (1965) conducted a chart audit to investigate the descriptive characteristics of obsessive compulsive neurosis in children aged 12 years or under. A total of 405 children from the child psychiatry service of UCLA Neuropsychiatric Institute were evaluated,

Table 1.3 Summary of OCD comorbidity among children and adolescents across a sample of studies

Author	*Study design*	*n*	*Assessment tool*	*Social phobia*	*SAD*	*GAD*	*Phobia*	*Depression (%) (n)*	*Tics/ Tourette's*	*ADHD*	*Disruptive behavioral*
Farrell et al. (2012)	Evaluated the effectiveness of group CBT on treatment outcomes: open trial	43	ADIS-IV-P	18.6 (8)	9.3 (4)	37.2 (16)	25.6 (11)	11.6 (5)	39.5 (17)	18.6 (8)	2.3 (1)
Ivarsson Melin, & Wallin (2008)	Investigated the presence of diagnostic heterogeneity in OCD. Within groups: age and gender	113	K-SADS-PL	7.1 (8)	4.4 (5)		24.8 (28)	24.8 (28)	27.4 (31)	17.7 (20)	8.8 (10)
Flament et al. (1990)	Prospective follow-up study (2–7 yr), OCD vs normal controls	27	DICA		7.4 (2)		3.7 (1)	22.6 (6)			11.1 (3)
Thomsen (1994)	Study of phenomenology and family functioning: OCD vs psychiatric control group	20	Child Assessment Schedule				20.0 (4)	40.0 (8)	50.0 (10)	30.0 (6)	10.0 (2)
Geller et al. (2001a)	Evaluation of chronological age and age at onset: children, adolescents with childhood onset, adolescents with adolescent onset	101	K-SADS-E	13.9 (14)	43.6 (44)		27.7 (28)	51.5 (52)	15.8 (16)	42.6 (43)	56.4 (57)
Storch et al. (2008)	Impact of severity and impairment on comorbidity with clinical sample	75	ADIS-IV-P	14.7 (11)		30.7 (23)		16.0 (12)		21.3 (16)	12.0 (9)
Geller et al. (2003a)	Impact of comorbidity on treatment response to Paroxetine: randomized control trial	335	K-SADS-PL		10.1 (34)	20.0 (67)	16.1 (54)	14.4 (48)	15.2 (51)	18.8 (63)	8.4 (28)
Masi et al. (2010)	The impact of gender, age at onset, phenotype and comorbidity with clinical sample: descriptive analyses	257	K-SADS-PL	38.1 (98)	28.4 (73)	39.3 (101)	18.3 (47)	27.2 (70)	31.6 (81)	17.1 (44)	31.9 (82)

Note: SAD = Separation Anxiety Disorder; GAD = Generalized Anxiety Disorder; ADHD = Attention Deficit/Hyperactivity Disorder; ADIS-IV-P = Anxiety Disorders Interview Schedule for DSM-IV: Parent Version (Silverman & Albano, 1996); K-SADS-PL = Kiddie Schedule for Affective Disorders and Schizophrenia for School-Age Children Present and Lifetime (Kaufman et al., 1997); DICA = Diagnostic Interview for Children and Adolescents (Herjanic & Campbell, 1977; Welner, Reich, Herjanic, Jung, & Amado, 1987); K-SADS-E = Kiddie-Schedule for Affective Disorders and Schizophrenia-Epidemiological Version (Orvaschel & Puig-Antich, 1994).

of whom 34 were described as having obsessive compulsive symptoms. Out of these, five children met criteria of what was described as obsessive compulsive neurosis, a point prevalence of 1.2%. Criteria for this review included well-defined obsessive compulsive symptoms; the symptoms had to be the most prominent evidence of psychopathology in the patient's clinical picture and had to impair the child's functioning.

These early clinical studies provided the foundation for child and adolescent OCD being recognized as a serious and relatively prevalent mental health condition. However, they are also reflective of an ascertainment bias as these studies were often carried out in predominately Caucasian areas on children and adolescents who have been referred for care, from middle- and upper-class families (Valleni-Basile et al., 1994). Indeed, prevalence estimates in OCD clinical samples often yield lower results as they can be biased toward more severe cases, and individuals with OCD are frequently secretive about their symptoms and wait until serious social interference occurs before seeking treatment (Zohar et al., 1992). Epidemiological research using large community samples have been able to overcome many of these limitations and provide more reliable estimates of the prevalence of mental health conditions in the general community.

In the 1980s, the National Institute of Mental Health (NIMH) published a longitudinal study of OCD in a community sample of 5,596 adolescents in 9th through 12th grades, across eight schools, assessed against specific criteria outlined in the DSM-III (APA, 1980). A point prevalence rate of 1%, and an estimated a lifetime prevalence rate of 1.9% was reported. The mean age of onset was found to be 12.8 years, with a male predominance. The most common obsessions concerned contamination or harm, and the most common compulsions were washing/cleaning, checking and straightening, with 70% of cases having multiple obsessions/compulsions. The prevalence estimate was hypothesized to be under estimating the true figure with the authors suggesting the most severe cases would not be attending school (Flament, 1988). This was the first study to suggest OCD was not a rare condition, but rather the disorder went largely unrecognized by health care professionals.

Valleni-Basile and colleagues (1994) investigated the prevalence of OCD in a community sample between 1986 and 1988. The sample consisted of more than 3,000 adolescents enrolled across four public middle schools. The reported prevalence rate was 3% and the prevalence of subclinical OCD was 19%. Prevalence for males and females was similar for the OCD group. The most commonly reported compulsions were arranging, counting, collecting, and washing. The nature of obsessions was not collected in this study based on the nature of the assessment interview (i.e., Schedule for Affective Disorders and Schizophrenia for School-Age Children; Chambers et al., 1985), which recorded only the presence of obsessions.

In a sample of 562 older adolescents (aged 16 and 17 years), who underwent mandatory screening for entry into the Israel Defense Force, Zohar and colleagues (1992) examined the prevalence of mental health problems, social functioning, and cognitive performance, using a structured interview schedule based on DSM-III-R (APA, 1987) criteria, which consisted of items from the Y-BOCS (Goodman et al., 1989) to screen for OCD. The induction centers screen over 95% of a complete national cohort of 16–17-year-old adolescents. Further, institutionalized individuals are able to be captured as they are assessed using their medical records. OCD caseness was present in 3.56% of the sample and an additional 1.25% of the sample were

identified as exhibiting OC symptomology. There was no significant sex differences found in the prevalence of the disorder.

A British Child Mental Health Survey of more than 10,000 young people aged 5–15 years was reported on by Heyman and colleagues (2001, 2003). The estimated point prevalence of OCD for the entire sample was 0.25% (95% CI 0.14–0.35). This study in particular captured younger prepubertal children, differing from many other studies which have largely only captured adolescents. Prevalence rates differed across age bands, with the incidence of OCD rising exponentially with increasing age: 5–7 years, 0.026% (95% CI 0.00–0.08); 8–10 years, 0.14% (95% CI 0.002–0.28); 11–12 years, 0.21% (95% CI 0.004–0.41); 13–15 years, 0.63% (95% CI 0.30–0.95). There was an equal distribution of gender across the sample. Among the children identified with OCD, almost 90% of cases had been undetected and untreated. This study had limitations in that lay interviewers were used and children under 11 years were not interviewed. A diagnosis was made by computer algorithm based on interview data and teacher reports.

Clinical characteristics of OCD were investigated by reviewing 11 childhood OCD clinic-based studies involving 419 children diagnosed with OCD. Geller and colleagues (1998b) found the average age of onset ranges between 7.5 and 12.5 years, with a mean of 10.3 years. Geller and colleagues also found a consensus in the literature for a male predominance in childhood OCD, with a 3:2 male–female ratio. Rapoport (1989) found that in an early onset of the disorder a male predominance was present; however, the male to female ratio becomes more equal with age and by late adolescence the ratio is even.

While these estimates suggest that OCD is indeed a relatively prevalent condition, the reality is that they are probably an underrepresentation of the real numbers of children and youth who suffer in silence. Children and adolescents with OCD are susceptible to underdiagnosis and undertreatment due to: (a) factors inherent to the disorder, such as secretiveness and lack of insight; (b) health care provider factors, such as incorrect diagnosis and either lack of familiarity with or unwillingness to use proven treatments; and (c) general factors, such as lack of access to treatment resources (Moore, Mariaskin, March, & Franklin, 2007). The disorder appears to have a similar prevalence to adults with the disorder, suggesting that not all cases of childhood OCD persist into adulthood as a cumulative prevalence of the disorder would be observed with new cases adding to the population over time (Geller, 1998a). However, unlike some other emotional disorders of childhood and adolescence, OCD appears to be persistent, with only a minority of sufferers recovering fully without treatment (Wilmshurst, 2005). Even with optimal treatment, an average of 50% of affected individuals continue to meet the diagnosis of OCD (Geller et al., 1998b).

Course

A meta-analysis and qualitative review of the long-term outcomes of child and adolescent onset OCD based on 16 studies with a total of 521 youth demonstrated that rates of persistence of OCD in childhood-onset cases are lower than previously believed (Stewart et al., 2004). Across follow-up periods ranging from 1 to 15.6 years, OCD was persistent in a mean of 60% of the pooled samples, indicating an overall