# Factors associated with poor response in cognitive-behavioral therapy for pediatric obsessive-compulsive disorder

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Cognitive-behavioral therapy (CBT) with exposure and response prevention has proved to be an effective intervention for youth with obsessive-compulsive disorder (OCD). Given advantages over psychiatric medications (i.e., serotonin reuptake inhibitors) based on superior safety, maintenance of response, and efficacy, CBT is considered the first-line treatment for youth with OCD. Nevertheless, a number of clinical factors can complicate CBT for OCD course and outcome. The authors review factors associated with poor treatment response, highlighting variables that pertain to the child, the family environment, and the treatment process. Specific topics include diminished insight, family accommodation, comorbidity, symptom presentation, and cognitive deficits. Remarkably, CBT for OCD is robust to these encumbrances in the majority of cases, despite the need for protocol modifications to tailor treatment to the individual child. (Bulletin of the Menninger Clinic, 74[2], 167-185)

Obsessive-compulsive disorder (OCD) among youth is more common than once believed, with point prevalence rates ranging from

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1% to 4% in the general child population (Douglass, Moffitt, Dar, McGee, & Silva, 1995; Zohar, 1999). As many as 80% of adult OCD cases have an onset during childhood (Pauls, Alsobrook, Goodman, Rasmussen, & Leckman, 1995), with the initial peak of incidence around puberty and subsequently in young adulthood (Geller et al., 1998). The occurrence of pediatric OCD may be somewhat higher than published reports given child secrecy in reporting embarrassing thoughts/behaviors, particularly those involving aggressive, sexual, and religious themes. Additionally, limited insight, parental difficulty in recognizing symptoms, and the lack of awareness about the availability of efficacious treatment may contribute to underdiagnosis and treatment practice that does not adhere to clinical guidelines (Jenike, 1989).

Given the above, it is not surprising that pediatric OCD causes substantial distress and is related to pervasive impairments in social, family, and academic functioning (Piacentini, Bergman, Keller, & McCracken, 2003; Piacentini, Peris, Bergman, Chang, & Jaffer, 2007). In the absence of appropriate intervention, symptoms run a chronic or fluctuating course into adulthood (Bloch et al., 2009; Flament et al., 1990) and continue to exert a negative impact on functioning and quality of life (Hollander et al., 1996; Koran, 2000; Piacentini et al., 2003), as well as psychiatric comorbidity (e.g., depression, substance use; Rosario-Campos et al., 2001).

#### Treatment of Pediatric OCD

Given the distressing and impairing nature of pediatric OCD, the development of effective treatments has been a priority for researchers and clinicians alike. Given this, the past decades have witnessed a surge of treatment-related research with perhaps the most significant advances including the application of cognitive-behavioral therapy (CBT) and serotonergic medications to pediatric populations. At present, two treatment modalities are empirically supported: CBT with exposure and response prevention (E/RP) (hereafter referred to as CBT) and pharmacotherapy involving selective serotonin reuptake inhibitors (SRI).

# Cognitive-Behavioral Therapy

Currently, CBT (alone or with a concurrent SRI medication) is recommended as the first-line treatment for pediatric OCD (AACAP, 1998; Lewin & Piacentini, 2009; POTS, 2004). Although individual treatment protocols may differ slightly as a function of various components (e.g., degree of family involvement), each consists of three central components: exposure (placing the patient in situations that elicit obsessional anxiety); response prevention (refraining from engaging in compulsions that function to reduce or avoid anxiety); and cognitive therapy (training the child to identify and reframe anxiety-provoking cognitions).

Four controlled CBT trials have recently been published examining CBT among pediatric OCD patients. The Pediatric Obsessive-Compulsive Treatment Study team (POTS, 2004) conducted a large-scale, multisite, randomized, placebo-controlled trial of CBT, sertraline, and combination treatment in 117 children ages 7-17 years. Overall, CBT alone or sertraline alone was superior to placebo, but there was an additional advantage for combined treatment. Barrett, Healy-Farrell, and March (2004) compared the efficacy of individual cognitive-behavioral family-based therapy (CBFT), group CBFT, and a wait-list control condition in a sample of 77 pediatric OCD patients. Marked improvements were found within both CBFT conditions (which did not differ) on symptom severity and diagnostic status change. Furthermore, results were maintained at 6 months: 65% of individual and 87% of group CBGT participants were OCD diagnosis free. De Haan, Hoogduin, Buitelaar, & Keijsers (1998) compared the effectiveness of E/RP (without a large cognitive component) to clomipramine in 22 youth with OCD. Although significant improvements were found in both conditions, E/RP was associated with greater improvement on the Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS; Scahill et al., 1997). Finally, Storch et al. (2007a) demonstrated the efficacy and relative similarity of intensive and weekly CBT in a sample of 40 youth (Storch et al., 2007b). Overall, gains associated with CBT are durable, with effects being maintained several years posttreatment (i.e., Barrett, Farrell, Dadds, & Boulter, 2005; O'Leary, Barrett, & Fjermestad, 2009).

## Psychopharmacological Therapy

Randomized, placebo-controlled trials have demonstrated the efficacy of clomipramine, sertraline, fluoxetine, paroxetine, and fluvoxamine for pediatric OCD (see Geller et al., 2003a, for a review; Geller et al., 2003b). Response rates have generally been modest, ranging from 30% to 74% (Cook et al., 2001; DeVeaugh-Geiss et al., 1992; Geller et al., 2001; Geller et al., 2004; Liebowitz et al., 2002; March et al., 1998; POTS, 2004; Riddle, Hardin, King, Scahill, & Woolston, 1990; Riddle et al., 2001). Overall, although significantly better than placebo--and considered generally safe and readily disseminated--SRI treatment for pediatric OCD is associated with modest effect sizes, the frequent presence of residual symptoms, and differential response as a function of comorbidity (Geller et al., 2003a). Furthermore, because of the risk profile, adverse effects, and required EKG and blood-level monitoring associated with clomipramine (e.g., antiadrenergic, anticholinergic, and antihistaminergic adverse effects), SSRIs (with a relatively minimal side effect profile) are the consensus first-line medication for pediatric OCD (AACAP, 1998; Grados, Scahill, & Riddle, 1999; Lewin, Storch, Adkins, Murphy, & Geffken, 2005a). Recent research suggests that the specific choice of medications should be based on the patient's medical history, concomitant medications, and the adverse events profile (Geller et al., 2003b).

#### Factors Associated with Poor CBT Response

Overall, CBT is an effective intervention with some advantages over medications in terms of both efficacy and safety. For example, SRIs have been linked with a number of side effects, most notably behavioral activation, that can cause treatment discontinuation (Murphy, Segarra, Storch, & Goodman, 2008). CBT for pediatric OCD also appears more effective than SRIs acutely with enduring effects following conclusion of treatment (Lewin & Piacentini, 2009). Despite the advantage of efficacy, several limitations of CBT are notable. Not all youth respond to CBT, and adherence can be a problem to exposure-based tasks, particularly among patients with comorbid conditions. A number of patients with OCD cannot tolerate being exposed to feared stimuli, and approximately 30%

demonstrate little or no improvement (Piacentini, Bergman, Jacobs, McCracken, & Kretchman, 2002; POTS, 2004). Furthermore, as detailed below, a number of factors may be associated with attenuated response, such as initial symptom severity and impairment, oppositionality and severe depression, low patient motivation, and symptom typology (e.g., sexual/religious obsessions; e.g., Alonso et al., 2001; Mataix-Cols, Marks, Greist, Kobak, & Baer, 2002; Piacentini, 2008; Steketee, Chambless, & Tran, 2001; Storch et al., 2006a; Storch et al., 2008b). In addition, CBT has not been widely disseminated, with much of the CBT research being conducted at specialized academic centers rather than in routine clinic settings. Patient access to CBT is also limited by the availability of trained therapists (Lewin et al., 2005a) and the considerable time and cost (including insurance reimbursement issues) requirements of treatment.

In understanding the reasons for non- or partial response, several factors have been identified through empirical investigation in youth, extrapolations from adult data, and clinical experience. In the text that follows, factors associated with poor treatment response are reviewed, highlighting variables that pertain to the child, the familial environment, and the treatment process.

## Insight

Insight is considered to play a significant role in treatment outcome and has been investigated considerably among adult OCD patients (Catapano et al., 2009; Catapano, Sperandeo, Perris, Lanzaro, & Maj, 2001; Erzegovesi et al., 2001) and in two studies in youth (Lewin et al., in press; Storch et al., 2008c). Per the *DSM-IV-TR* (and previous versions), individuals with OCD must understand that their obsessions and compulsions are irrational, excessive, and senseless despite their often irresistible urges to engage in rituals (American Psychiatric Association, 2000). However, many patients with OCD, particularly youth, do not fully recognize the excessive and unreasonable nature of their obsessions or compulsions (Bellino, Patria, Ziero, & Bogetto, 2005).

Some studies have found that limited insight was associated with decreased patient resistance to obsessions and compulsions, which contributed to poorer treatment outcomes (Catapano et al., 2001; Turksov, Tukel, Ozdemir, & Karali, 2002). In a study focused on insight among 78 pediatric OCD patients, Storch et al. (2008b) found that 45% exhibited low levels of insight into their symptoms based on CY-BOCS item 11 (Scahill et al., 1997). Insight was inversely related to OCD symptom severity, and patients with limited insight were rated by their parents as more impaired and needing family accommodation of symptoms. More recently, Lewin et al. (in press) found that poor insight was associated with reduced perception of environmental control, increased depressive symptoms, and diminished intellectual functioning. Indeed, findings such as these suggest that patients, both youth and adult, who do not recognize the irrationality of their thoughts and behaviors are less able to challenge them and consequently have a worse prognosis (O'Dwyer & Marks, 2000). These individuals tend to be less likely to present for treatment than those with good insight, and clinical experience suggests that compliance and motivation tend to be lower.

## Family Accommodation

Family accommodation refers to actions taken by family members to facilitate rituals (e.g., provide objects needed for rituals, hear "confessions"), provide reassurance related to symptoms, acquiesce to the child's demands (e.g., not entering a room because it will contaminate that area), decrease child day-to-day responsibility (e.g., allow the affected child to "get out" of chores or other responsibilities), or assist with/complete tasks for the child (e.g., turn water off/on, flush the toilet) (Waters & Barrett, 2000). Given the salience of family for children, families have frequent opportunities to encounter their child's symptoms and, through their involvement and accommodation of symptoms, potentially maintain them (Lenane et al., 1990).

It is quite clear that accommodation is often fueled by family members' efforts to reduce the child's ritual engagement, distress, or functional impairment. Unfortunately, such efforts have the "side effect" of reinforcing the child's symptoms and significantly impacting family members' lives (Steketee & Van Noppen, 2003). Currently, there is an increasing body of literature focused on family accommodation of symptoms. Until recently, most work was

completed in primarily adult samples of OCD patients, finding that accommodation is quite common (Calvocoressi et al., 1995; Calvocoressi et al., 1999; Shafran, Ralph, & Tallis, 1995), correlated negatively with family functioning, and correlated positively with family stress (Calvocoressi et al., 1995) and symptom severity (Amir, Freshman, & Foa, 2000; Calvocoressi et al., 1999). Additionally, accommodation was associated with depressive and anxiety symptoms in the patients' relatives (Amir et al., 2000).

Currently, relatively little has been reported on family accommodation in pediatric samples despite estimates that it takes place in a majority of cases (Merlo, Lehmkuhl, Geffken, & Storch, 2009; Peris et al., 2008; Storch et al., 2007a). Storch et al. (2007a) reported that greater OCD severity led to increased family accommodation, which in turn resulted in elevated functional impairment. Moreover, Merlo et al. (2009) found that reductions in family accommodation related to better CBT treatment outcome. With this in mind, recent advances in pediatric OCD treatment have focused on the need to incorporate family members in efforts to reduce levels of accommodation (e.g., Barrett et al., 2004; Storch et al., 2007b).

## Comorbidity

Psychiatric comorbidity is one factor that exerts a significant impact on clinical course and treatment outcome. Several disorders, in particular, are thought to be related to poor CBT response by requiring clinician attention to both OCD and the co-occurring condition: depressive disorders, disruptive behavior disorders, and ADHD. Similarly, there may be particular mechanisms specific to comorbid disorders that impact outcome. For example, the presence of depressive disorders may be associated with reduced anxiety habituation during exposures (Abramowitz, 2004), as well as decreased hope that treatment might work or motivation/energy to engage in exposures. Comorbid disruptive behavior disorders can be problematic by virtue of their association with patient resistance and secondary gains that make youth less motivated to reduce symptoms. Finally, significant inattention and/or hyperactivity symptoms conflict with the ability to attend to concepts discussed within therapy (Rapee, 2003) and are associated with

deficits in executive functioning that are related to independently conducting therapeutic tasks (e.g., exposures; Olley, Malhi, & Sachdev, 2007).

Although the pediatric OCD literature on this topic is limited, adult findings indicate that depression is negatively related to outcome (Abramowitz & Foa, 2000; Steketee et al., 2001). Comorbid anxiety disorders have generally not shown any effect. Among children, the presence of ADHD and disruptive behavior disorders was found to be related to lower response rates to 14 family-based CBT sessions (n = 96), and disruptive behavior disorders and major depression were related to lower remission rates (Storch et al., 2008b). In a post-hoc examination of treatment response to paroxetine, Geller et al. (2003b) found that relative to youth without a comorbidity (75% were responders), those with ADHD, tics, and oppositional defiant disorder (ODD) exhibited significantly worse response (56%, 53%, and 39%, respectively). Others have also shown that the presence of a comorbid tic disorder negatively impacts pharmacotherapy response but not CBT response (Grados & Riddle, 2008; March et al., 2007; McDougle et al., 1993).

#### Symptom Presentation

OCD varies from other anxiety disorders in its heterogeneous presentation that spans numerous types of symptoms. Symptom presentation can vary considerably between people, with symptom clusters identified through factor analyses showing four- or five-factor solutions consisting of: (1) symmetry/ordering, (2) contamination/cleaning, (3) sexual/religious obsessions, (4) aggressive/checking, and (5) hoarding dimensions (Mataix-Cols, Rosario-Campos, & Leckman, 2005). In light of such heterogeneity, researchers have questioned if treatment outcome may be a function of symptom predominance.

Within the extant literature, CBT response has been attenuated in patients with hoarding symptoms (Abramowitz, Franklin, Schwartz, & Furr, 2003; Bloch et al., 2009) and primarily obsessional symptoms (Alonso et al., 2001; Rufer et al., 2006). In contrast, contamination and checking symptoms have been associated with a generally positive response (Abramowitz et al., 2003). Like the other factors previously reviewed, relatively little has been re-

ported on how CBT outcome differs as a function of symptom typology in pediatric patients. One exception is Storch et al. (2008a), who examined how symptom dimensions on the CY-BOCS Symptom Checklist were associated with CBT outcome in 92 children and adolescents with OCD. Findings indicated that those with aggressive/checking symptoms exhibited improved treatment response relative to those without any aggressive/checking symptoms (Storch et al., 2008a). In addition, higher scores on the aggressive/checking dimension predicted treatment-related change in the CGI-Severity index, but not the CY-BOCS. Other dimensions were not associated with treatment response.

#### PANDAS

Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus (PANDAS) are characterized by the presence of OCD and/or tic disorder, prepubertal onset of these symptoms, episodic symptom severity, and a temporal association with group A streptococcal (GAS) infections (Murphy & Pichichero, 2002; Murphy, Sajid, & Goodman, 2006; Swedo et al., 1998). Symptoms present abruptly and have an episodic course, with the majority of patients enduring one or more future symptom recurrences (Murphy et al., 2004). Traditional pharmacological approaches, such as SRI therapy, may not share the same efficacy as in non-PANDAS cases and may be associated with elevated rates of behavioral activation (Murphy, Storch, & Munson, 2006). Finally, several studies have investigated antibiotic prophylaxis in treating PANDAS-related symptoms. Similar to above, these approaches have promise, but the studies have produced inconsistent results (see Murphy et al., 2006, for a review)

Currently, only two reports of CBT for PANDAS have been reported (Storch et al., 2004; Storch et al., 2006b). Storch et al. (2004) reported a case suggesting the effectiveness of CBT in a 6-year-old boy who experienced rapid-onset OCD symptoms of the PANDAS phenotype. Following 1 week of intensive CBT, the boy evidenced marked symptom reductions as assessed by the CYBOCS (Pretreatment of 34, Posttreatment of 8); treatment gains were maintained for one-year. In the most rigorous report to date, Storch et al. (2006b) provided seven children with OCD of the

PANDAS subtype (ages = 9-13 years) 3weeks of intensive family-based CBT using a wait-list control design. No changes took place over the initial 4-week wait-list. Immediately following the treatment phase, six of the seven youth were treatment responders (much or very much improved), and three of six remained responders at 3-month follow-up. Effect sizes associated with treatment were large, with an effect size of 3.38 characterizing the CY-BOCS reduction.

# Cognitive and Developmental Issues

It has long been assumed that certain comorbid developmental and cognitive disorders interfere with the implementation of CBT for OCD. These disorders include, but are not limited to, autism, Asperger syndrome, Prader-Willi syndrome, Down syndrome, and mental retardation. Surprisingly, very little research has been published regarding the effects of these conditions on the outcomes of CBT for OCD. Autism and autism spectrum disorder traits have also been found to be common in pediatric OCD patients (Ivarsson & Melin, 2008), with as many as 37% of youth with autism being reported to have comorbid OCD (Leyfer et al., 2006). The presence of a comorbid autism spectrum disorder typically necessitates modification to CBT (Lewin et al., 2005b) and can result in favorable outcomes (Lehmkuhl, Storch, Bodfish, & Geffken, 2008). Whereas intellectual and communication deficits may inhibit CBT for youth with autism, concreteness and inflexibility can complicate CBT for youth with Asperger's disorder even in the absence of language or cognitive impairments. Consequently, youth with Asperger's disorder may benefit from CBT with less of a cognitive emphasis (i.e., more behaviorally focused, including a program of incentives for participation) (Lewin et al., 2005b). Work by Wood and colleagues (2009) has focused on refining CBT to make it more accessible for higher functioning youth with autism.

Genetic disorders such as Prader-Willi syndrome (PWS) and Down syndrome can complicate CBT for OCD. PWS is a complex genetic disorder characterized by mild mental retardation, unremitting food-seeking behavior, stubbornness, and aggressive outbursts. Although both food-related and non-food-related obsessions and compulsions (e.g., hoarding, symmetry, need for exactness, contamination, cleaning, ordering, arranging, and need to confess/tell) are common among individuals with PWS (Dykens, Leckman, & Cassidy, 1996), no published reports exist regarding the treatment of OCD symptoms in PWS. However, Dykens et al. stated that behavioral approaches "have had limited success in decreasing food obsessions in PWS" but "may, however, be more helpful in reducing non-food compulsions" (p. 1000). Some of us are currently working on adapting CBT for use in PWS; preliminary results are promising. Individuals with Down syndrome (a chromosomal disorder characterized by impairment in cognitive ability and in physical growth and development) have a relatively high prevalence of OCD (4.5%) (Prasher & Day, 1995). Among individuals with Down syndrome and OCD, obsessional slowness, need for exactness, and ordering/arranging are symptoms that commonly emerge (Prasher & Day, 1995) The authors concluded that behavioral strategies such as shaping and pacing "were of some benefit" (p. 323) in reducing slowness, even though they "were not tried in a systematic or consistent manner" (Charlot, Fox, & Friedlander, 2002).

Common among most of the aforementioned conditions is impairment in intellectual functioning. Thus, not surprisingly, youth with borderline intellectual abilities or mental retardation (i.e., IQ of about 70 or below, and impairments in adaptive functioning) can impede CBT for OCD. Nevertheless, behavioral approaches (differential reinforcement, overcorrection, and in vivo exposure) have proved useful for compulsive checking (Matson, 1982), and there is some evidence that CBT can be tailored for use in those with borderline intellectual abilities (Pence, Aldea, & Storch, in press).

In summary, OCD and OCD tendencies commonly co-occur in individuals with cognitive disabilities. Despite this fact, very little research has been published describing the application of CBT to treat OCD among individuals with these conditions. Hence there is the erroneous thought that OCD among these youth can be treated only with neuroleptics. Despite a lack of controlled trials of CBT for youth with intellectual delays, several case studies or series il-

lustrate that CBT with modifications can be effective for individuals with cognitive impairments and/or autism spectrum disorders (Lehmkuhl et al., 2008; Pence et al., in press; Raven & Hepburn, 2003). These case studies suggest that modifications may be essential and emphasize the addition of other behavioral techniques (e.g., shaping, differential reinforcement) to reduce OCD symptoms in these populations. In summary, Pence et al. (in press) suggest that the following four modification strategies to the standard CBT protocol be considered: (1) added parental involvement, (2) simplified language, (3) decreased reliance on cognitive procedures, and finally (4) the use of contingency management and parental/therapist role models.

#### Conclusions and Future Directions

Despite the negative impact associated with a number of the aforementioned factors (e.g., comorbidity, developmental and cognitive barriers, poor insight, family dynamics), children's responses to CBT for OCD are relatively robust. Modifications to protocols outlined in CBT manuals may be required; however, the principal components of CBT for OCD remain intact (i.e., exposure and response prevention). The advent of the evidence-based treatment movement has emphasized an understanding of for whom specific treatments work, as well as how treatments produce clinical change (i.e., "active ingredients" of a particular treatment) (Kraemer, Wilson, Fairburn, & Agras, 2002). An understanding of treatment response profiles and mechanisms of change can inform efforts to individualize treatments to particular patients based on identification of the barriers discussed in this review. Nevertheless, more systematic investigation regarding modular components of CBT (e.g., developed to supplement treatment for youth with poor insight or autism spectrum disorders or comorbid depression) are necessary so that efficacious and cost-effective revisions to CBT for OCD can be more readily available in clinical practice.

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