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Phenomenology of Early Childhood Onset Obsessive Compulsive Disorder

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Abstract

This paper describes the phenomenological features of early childhood onset obsessive compulsive disorder (OCD; defined as children meeting DSM-IV criteria for OCD with age of onset <8 years). Fifty-eight children (ages 4–8) were included in the sample. OCD and comorbid diagnoses were determined by structured interview, and OCD severity was measured using the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS). Mean age of OCD onset was almost five, and mean age of presentation was between 6 and 7. Mean symptom severity was in the moderately severe range. Comorbidity and family history of OCD were common. Contamination and aggressive/catastrophic obsessions and washing and checking compulsions were endorsed most frequently. Results indicate that early childhood onset OCD may have a lower boy to girl ratio and lower rates of depressive disorders, but may be similar to later childhood onset OCD in terms of OCD symptom presentation and severity.

Keywords

Child; OCD; Phenomenology

Despite a common core of symptoms observed across the lifespan, recent research has suggested that obsessive compulsive disorder (OCD) with onset in childhood may have unique phenomenological features and risk factors relative to adult cases. To date, the term *juvenile onset* has been used to refer to cases that begin at any point in childhood or adolescence. Although OCD has been documented in children as young as age three (Hollingsworth et al. 1980; Zohar 1999) children with early childhood onset have been poorly represented in previously published juvenile samples.

Prior studies of juvenile OCD have reported a mean age of OCD onset of about 10 years (range 6–14 years) and have varied widely in terms of the mean chronological age of the sample at the time of assessment (range 9–19). These studies have suggested that, relative to adult cases, juvenile cases show: a male preponderance (Hanna 1995; Masi et al. 2005, 2006; Swedo et al. 1989), familial aggregation of OCD and tic disorders (Chabane et al. 2005; Lenane et al. 1990; Nestadt et al. 2000; Pauls et al. 1995), and high rates of psychiatric comorbidity, especially with disruptive behavior disorders, other anxiety disorders, and tic disorders (Chabane et al. 2005; Chowdhury et al. 2004; Geller et al. 1996, 1998; Leonard et al. 1992; Masi et al. 2006; Rosario-Campos et al. 2005; Swedo et al. 1989). Further, juvenile cases are more likely to present with compulsions only (Geller et al. 1996, 1998; Rettew et al. 1992; Swedo et al. 1989), higher rates of aggressive obsessions, and higher rates of hoarding (Geller et al. 1998, 2001a). In addition, their compulsions may be difficult to differentiate from tics (Eischstedt and Arnold 2001).

It remains unclear whether there are developmental differences in phenotypic presentation within the juvenile age range, particularly with respect to features that characterize OCD with early childhood onset. For example, Rettew et al. (1992) reported that relative to the rest of their juvenile onset sample, there was a higher frequency of atypical obsessions or compulsions (e.g., blinking or breathing rituals) among the 12 participants who reported that their OCD symptoms began before age six.

More recently, Geller et al. (2001b) concluded that both age of onset and age at the time of assessment are important variables in understanding juvenile OCD. They found that, regardless of age of assessment, younger age of onset was associated with higher rates of ADHD and non-OCD anxiety disorders. Presence of comorbid mood disorders and psychotic symptoms and history of psychiatric hospitalization were related to age at the time of assessment and not to age of OCD onset, with older youth having higher rates of both. Comorbidity with tic disorders was associated with younger age at time of assessment. Although these results fill in many gaps in the understanding of juvenile onset OCD, they may not adequately address the phenomenon in the youngest end of the age spectrum.

Prior research has suggested that several age-related changes in children's self-understanding occur around age eight (Secord and Peevers 1974; Selman 1980). Therefore, assessment of phenomenological features prior to this age must be developmentally tailored. Because the focus of prior research has been on children over eight, it is possible that the methods used (i.e., which instruments were used and how those instruments were administered) in those studies were better suited for use with older children and adolescents. Therefore, even when young children were included in previous reports, information obtained from them may have been less reliable and valid than information obtained from older children. In contrast, the present work focuses specifically on this age range, and age-appropriate interviewing techniques for young children and their parents were specifically developed. For example, the rating scale used to code information about symptom severity has fewer anchors and each is associated with a picture illustrating that level of distress.

The purpose of this study was to describe the phenomenological characteristics and clinical correlates associated with early childhood onset OCD (age of onset <8) among children presenting for evaluation or treatment during this same developmental period. Based on previous research, the following features and correlates were of interest: (1) proportion of boys, (2) comorbidity, (3) rates of family history of OCD and tic disorders, (4) compulsions without obsessions, (5) types of obsessions and compulsions, and (6) tic-like compulsions. The relationship between proband gender and age with these characteristics was also examined.

Method

Participants

The sample consisted of a subset of children referred to the Bradley-Hasbro Pediatric Anxiety Research Clinic (PARC), a specialty psychology/psychiatry clinic housed within a major medical center. Children were included if they were age eight or younger at the time of the assessment and had a structured interview-determined primary diagnosis of OCD. Age of onset was determined by parent and child report during the structured interviews. Children in the sample were recruited for one of several ongoing research studies at PARC or were clinical referrals from the community. The intake procedure at PARC is multi-step. First, parents complete a telephone screen with a research assistant. During the timeframe considered in this study, 266 telephone screens of children age eight and under were completed. Children who had no symptoms of possible OCD, or who had previously diagnosed developmental disabilities were not invited for in-person assessments ($n=116$). Of the 150 children who received in-person evaluations, 92 were excluded because they did not receive a diagnosis of OCD via structured interview and Children Yale-Brown Obsessive Compulsive Scale (CYBOCS) assessment. This resulted in a sample of 58 children age eight or younger who met DSM-IV criteria for OCD.

Measures

Kiddie-Schedule for Affective Disorders and Schizophrenia—5th edition (K-SADS; Kaufman et al. 1997)—The K-SADS is a widely used semi-structured, clinician rated interview that assesses the major Axis I domains. It possesses favorable psychometric properties (Chambers 1985; Kaufman et al. 1997).

Anxiety Disorders Interview Schedule for DSM-IV, Child Version (ADIS-IV-C; Silverman and Albano 1996)—The ADIS-IV-C is a structured clinical interview that is specifically designed to assess DSM-IV childhood anxiety disorders and related mood disorders. It also allows the clinician to rule out alternative Axis I diagnoses such as behavior disorders. The DSM-III-R version of the ADIS-C has been widely used and has good interrater and retest reliability (Silverman and Eisen 1992; Silverman and Nelles 1988; Silverman and Rabian 1995). These properties are believed to hold for the DSM-IV version. In addition, concurrent validity of the anxiety disorders sections of the DSM-IV version is strong (Wood et al. 2002)

Child Yale Brown Obsessive Compulsive Scale (CYBOCS; Scahill et al. 1997)—The CYBOCS is a widely used ten item semi-structured clinician-rated instrument that is designed to assess presence and severity of current OCD. Obsessions and compulsions are each rated using a five-point scale assessing multiple domains related to OCD symptom severity, including time, interference, distress, resistance, and control. The CYBOCS yields a total obsession score, a total compulsion score, and a combined total score with higher scores indicating more severe symptoms. The CYBOCS has adequate convergent and divergent validity (Storch et al. 2006; Yucelen et al. 2006).

All children received a CYBOCS. Children received an ADIS or KSADS depending on the research study in which they participated. All assessments were conducted jointly with parents and children by doctoral-level (Ph.D. or M.D.) clinicians who were specially trained to administer these instruments to young children. When parent report and child report were discrepant, both points of view were recorded and clinical judgment was used to determine which point of view to weight more heavily in arriving at final diagnostic decisions. Most participants completed all assessments in a single visit. Due to child fatigue, occasionally a second visit was used to complete the assessments.

In addition to the structured assessments, parents provided detailed background, developmental, and demographic information as well as current and past treatment history. The data included in this study were obtained under the approval of the hospital IRB. Informed consent was obtained from parents. All children provided verbal assent, and those who were capable provided written assent.

Data Analytic Approach

Descriptive statistics were used for within sample analyses. For inferential analyses, *t*-tests or analyses of variance were used for continuous variables and chi-square tests were used for categorical data. All tests were two-tailed. By definition, age of onset is confounded with age at presentation (e.g., it is impossible to have an age of onset of eight if the age at presentation is less than eight). Results will be confounded in this manner if the age of presentation is positively correlated with the dependent variable of interest. Following the guidelines of Weinberg (1993) in cases where there was a significant positive association between age of presentation and a dependent variable of interest, age of presentation was included as a covariate in the analysis assessing the significance of age of onset.

Results

Demographic Characteristics

Demographic data are presented in Table 1. The sample consisted of 58 children (23 boys and 35 girls), which does not reflect a male preponderance ($Z_{UN}=1.44, p=.93$). The sample was predominantly Caucasian (92.60%). Hollings-head Ratings were calculated using the two factor index of socioeconomic status (Hollingsworth et al. 1980). In two-parent families, the higher social class of the two was used for analysis. Twenty-four percent of the sample had received previous psychological testing, 19% had been treated with medication, and 24% had received some form of previous psychotherapy.

OCD Severity and Course

Severity and course data are presented in Table 2. The sample had a mean CYBOCS score of 23.07 ($SD=4.78$), which is at the high end of the moderate range of symptom severity. CYBOCS scores were negatively correlated with age of OCD onset ($r=-.28, p=.04$), but were not correlated with age of presentation ($r=-.06, p=.67$). There was no effect of gender on CYBOCS scores ($t(56)=-.65, p=.52$). The mean age of OCD onset was 4.95 years ($SD=1.52$, range = 2–6) and the mean age of presentation was 6.72 years ($SD=1.26$, range 4–8). The mean onset-presentation latency was 1.72 years ($SD=1.50$). Boys did not differ from girls in age of onset ($t(49)=0.65, p=.52$) or age of presentation ($t(56)=-.77, p=.44$). Regarding type of OCD onset, 14 (24%) had an abrupt onset, 29 (50%) had a gradual onset, and 15 (26%) had no information about type of onset. In terms of OCD course, 17 (29%) had a chronic course, 16 (28%) had a waxing and waning course, 10 (17%) had an episodic course, three (5%) were within 2 months of the evaluation and the course was not yet known, and 12 (21%) had no information about course. Relative to those with a gradual onset, children with an abrupt onset of OCD symptoms were more likely to have an episodic course ($\chi^2(2)=9.46, p=.01$; adjusted residual=3.00). Boys

did not differ from girls in type of onset ($\chi^2(1)=0.95, p=.33$). Girls were more likely than boys to have a continuous or chronic course ($\chi^2(2)=5.89, p=.05$; adjusted residual=2.40). Children with a gradual onset had an earlier age of onset of OCD than children with an abrupt onset ($t(37)=2.35, p=.02$). No differences in age at time of presentation were noted for type of onset ($t(41)=-.27, p=.79$) or type of course ($F(2,40)=0.09, p=.92$). Similarly, no differences were found in age of onset for type of course ($F(2,39)=1.36, p=.27$).

Family History

Twenty percent reported a first-degree family history of OCD, 14% reported a first-degree family history of a Tic Disorder, and 32% reported a first-degree family history of an anxiety disorder other than OCD. Age of onset, age of presentation, and gender were not related to any family history variables, with the exception that girls were more likely than boys to have a first-degree family history of a tic disorder ($\chi^2(2)=4.06, p=.04$; adjusted residual=2.0).

Comorbid Conditions

Seven (12%) children did not meet criteria for any diagnosis other than OCD. Comorbid full and provisional diagnoses, as identified in structured interviews, are provided in Table 3. Consistent with the DSM-IV, a designation of “provisional” was used to refer to cases in which the clinician administering the structured interview either was not able to obtain enough information to feel confident in assigning the diagnosis (e.g., due to child’s inability to adequately describe internal phenomena), or several of the key features of a particular disorder were endorsed but other criteria required for a full diagnosis were not fulfilled. The rationale for including provisional diagnoses was that some children, given the young age of presentation, might be showing early symptoms of the disorder but not to the degree or duration that would warrant a full diagnosis. Overall, boys and girls did not differ on presence ($\chi^2(1)=0.03, p=.85$) or number ($t(56)=0.68, p=.49$) of comorbid conditions. There were no associations between gender and comorbidity. Diagnostic category was not associated with age of OCD onset or presentation except that children with comorbid ODD had an earlier age of OCD onset than children without ODD ($t(49)=2.56, p=.01$). There was insufficient sample size to examine these relationships for panic disorder and Tourette’s Disorder.

Presence of Specific Obsessions and Compulsions

Rates of specific obsessions and compulsions are presented in Table 4 and Table 5. Seventy-five percent of the sample endorsed multiple obsessions with an average of 2.41 ($SD=1.51$) obsessions. Contamination and aggressive/catastrophic obsessions were endorsed most frequently. Ninety-six percent of the sample endorsed multiple compulsions, with an average of 4.14 ($SD=1.18$) compulsions. Washing and checking compulsions were the most common. Eighteen percent of the sample endorsed compulsions in the absence of obsessions. A few relationships were observed between child age and presence of specific obsessions or compulsions. Children with checking compulsions were older than those without ($t(49)=2.38, p=.02$); children with rubbing compulsions were younger than those without ($t(29)=3.20, p<.01$).

Based on the definition used by Rosario-Campos et al. (2001) information obtained from the CYBOCS was collapsed to form a variable called “tic-like compulsions”. These compulsions include touching, tapping and rubbing rituals as well as other behaviors that children reported needing to perform “until it feels just right” to relieve distress. Twenty-six percent of the sample endorsed “tic-like” compulsions. Of those 15 cases with tic-like compulsions, one met criteria for a full tic disorder and three had a rule out tic disorder.

Discussion

This paper reports on a sample of children with OCD who were different from previously reported samples of juvenile OCD in two important ways. First, they were younger at the time of assessment, and second they had an earlier age of OCD onset. Results suggest that children with early childhood onset OCD share similarities in terms of symptom presentation and severity with their older counterparts, suggesting that this is a sample with full-blown OCD and not a prodromal phase or subthreshold version of the illness. However, the early childhood onset group also demonstrated some important differences from children with older juvenile onset.

Consistent with overall trends in pediatric samples (Geller et al 1998) and despite their young age, the majority of children had multiple diagnoses. In comparison to previously described samples with juvenile onset OCD, similar comorbidity rates were found for many of the anxiety disorders (i.e., GAD, specific phobias, and SAD) (Geller et al. 2001a; Masi et al. 2005). However, lower rates were found for the depressive disorders (Geller et al. 2001a; Masi et al. 2005). The lower rates for depressive disorders are consistent with what one would expect based on general developmental trends (Costello et al. 2003), as well as based on previously published data about the age of onset of depression as a comorbid condition among youth with OCD (Geller et al. 1996).

Regarding obsessive and compulsive symptoms, this sample endorsed a mean number of obsessions and compulsions similar to that reported previously (Hanna 1995). Aggressive and contamination obsessions were most common, and were endorsed at rates that were similar to those reported in older juvenile-onset samples (Geller et al. 2001a; Scahill et al. 2003; Swedo et al. 1989). However, religious/scrupulosity obsessions appear to be more common in this young sample than in older cohorts (Geller et al. 2001a; Scahill et al. 2003). In examining the content of the specific obsessions, this difference appears to be accounted for by the scrupulosity, rather than the religiosity, part of this category. Given that it is common for young children to be rule governed and have black and white definitions of right and wrong (Francis and Gragg 1996), it is not surprising that OCD has attached itself to this developmental theme.

Some have posited that there is an early onset subtype of OCD. Hypothesized key features of this subtype include male preponderance, high rates of family history of OCD and/or tic disorders, and high rates of comorbidity with tic and disruptive behavior disorders. Twenty percent of the current sample reported a first-degree relative with OCD, which is within the range reported in juvenile cohorts (Chabane et al. 2005; Chowdhury et al. 2004; Geller et al. 1996). In addition, the rates of disruptive behavior disorders (ADHD, ODD, CD) and any tic disorder were within the range reported for older cohorts (Chowdhury et al. 2004; Geller et al. 2001a, b, 1996; Masi et al. 2005; Rosario-Campos et al. 2005). Therefore, these results support the familiarity and comorbidity features of the proposed early onset subtype. However, a male preponderance was not observed. Among the possible reasons for a lack of male preponderance could be that it was a spurious finding in previous research and is not in fact a core feature of early onset OCD. This hypothesis is supported by the fact that other studies have also failed to find a male preponderance in juvenile—or early—onset cases of OCD (Chabane et al. 2005; Chowdhury et al. 2004; Delorme et al. 2005; Last et al. 1992; Riddle et al. 1990; Rosario-Campos et al. 2001; Sobin et al. 2000). Alternatively, younger girls could be more verbal than younger boys and so would be able to make their need for help known earlier, and thus could be “over-” represented in a sample of younger participants. Clearly, data about verbal abilities would be needed to substantiate this interpretation.

Although one study of adults with early onset (<age 10) OCD reported that this group experienced greater symptom severity as adults relative to a group with later onset of OCD

(Rosario-Campos et al. 2001), this is the first study with a pediatric sample to find a simple inverse relationship between age of onset and symptom severity. Hanna (1995) found that boys with early onset and girls with later onset had the more severe symptoms. Geller et al. (2001a, b) and Scahill et al. (2003) did not find a relationship between age of presentation and symptom severity, and Geller et al. (2004) did not find a relationship with age of onset and symptom severity.

Another feature of the proposed early-onset OCD subtype is the presence of “tic-like” compulsions. Several researchers have reported that children with comorbid OCD and tic disorders are more likely to report the presence of repetitive behaviors that need to be performed until it feels “just right” (Leckman et al. 2000). Some have suggested that these symptoms reflect an overlap between the two disorders (Mansueto 2005; Woods et al. 2005). The task of differentiating rituals and complex tics was challenging in this young sample as complex tics are often topographically similar to rituals but are performed to alleviate unpleasant somatic symptoms (e.g., premonitory urges (Himle et al. 2007; Woods et al. 2005) rather than anxiety. Distinguishing and describing internal phenomena (such as anxiety or “premonitory urges”) likely requires relatively sophisticated cognitive and verbal abilities. In addition, given the potential relationship between tics and OCD in this young age range, it is possible that children might experience (and report) both complex tics and rituals. Cases in which children reported performing repetitive behaviors until something felt “just right” were classified as having tic-like compulsions. Although nearly a third of this sample (29%) reported tic-like compulsions, only about a quarter of these cases met criteria for a full or provisional tic diagnosis. Further research is needed to examine the nature and appropriate classification of “tic-like compulsions”, especially in terms of function and treatment response in young children.

Previous studies have also reported the occurrence of compulsions in the absence of obsessions in juvenile cohorts (Geller et al. 1996; Rettew et al. 1992; Swedo et al. 1989). Some may argue that these are cases where there is an unarticulated obsession or where the behavior may be more properly classified as a tic or another habit. As with tic-like compulsions, helping children articulate obsessions that are not in immediate awareness was difficult in this young sample. For example, several children endorsed complex sequences of behaviors that they felt the need to repeat, like arranging items on a nightstand at bedtime, but they were not able to articulate a feared consequence of not repeating the behaviors, nor were the behaviors of such short duration (e.g., tapping or touching) that they seemed more appropriately called a tic. Like tic-like compulsions, this is an area that also warrants further attention.

There is very little preexisting data against which to compare the results regarding type of symptom onset and course. In addition, although the presence of an episodic course reported by 17% children in this sample is interesting, the short latency between OCD onset and assessment in this study limits the ability to make statements regarding the longer-term course of OC symptoms. In terms of type of onset, the present rate of 24% with abrupt onset is similar to that from a sample of adults who retrospectively reported their type of onset (Millet et al. 2004). Among pediatric samples with OCD, an abrupt onset and episodic course, which were related in this sample, are two hallmark features of the research diagnostic criteria for Pediatric Autoimmune Neuropsychiatric Disorders Associated with a Streptococcal infection (PANDAS). None of the children in this sample met the research diagnostic criteria for PANDAS, but given their young age, and the fact that it takes time to establish a PANDAS diagnosis, it is possible that some of them may go on to do so in the future.

There are several limitations of this study that should be considered when interpreting the results. First, although it is the largest sample of young children with OCD published to date, tests of differences between subgroups may have been underpowered. Second, the sample was ascertained through a specialty clinic well known for the treatment of OCD and may not be

representative of the community. Third, although it was partially address by including provisional diagnoses in rates of comorbidity, the young age of the sample may have lead to underestimates of true rates of comorbid conditions, or may have produced rates that are not generalizable across age groups. Fourth, although family history data were compared to studies that had used similar methods, reliance on one parent's perspective is not ideal.

Nonetheless, this study offers a previously unavailable glimpse at which features and correlates emerge early in the course of the illness, close in time to age of onset. This approach is methodologically appealing in that there is a short latency between time of symptom onset and time of presentation for assessment, thereby lending credence to the reliability of the age of onset data. Some similarities and some differences between this early childhood onset cohort and previously reported older juvenile cohorts were found. The results add weight to the growing body of evidence that male preponderance may not be a defining feature of juvenile onset OCD. Most importantly, these data provide evidence that young children have full-blown OCD and associated comorbidities. If left unrecognized or untreated, this group has an increased likelihood that OCD will severely disrupt normative development, impair functioning and extend into later childhood, adolescence and adulthood. Pilot data from a family-based cognitive-behavioral treatment program for this population is encouraging (Freeman et al. 2003, 2008), but further attention to this group in terms of assessment and treatment research is greatly needed.

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Table 1

Demographic characteristics

	<i>n</i>	%
Child gender: boys	23	40
SES Class I	9	16
SES Class II	14	24
SES Class III	11	19
SES Class IV	5	9
SES Class V	0	0

Table 2

Course and severity

	<i>n/mean</i>	<i>%/SD</i>	Range
CYBOCS score	23.07	4.78	11–34
Age of OCD onset	4.95	1.5	2–6
Age of presentation	6.72	1.27	4–8
Abrupt onset	14	24	N/A
Gradual onset	29	50	N/A
Chronic course	17	29	N/A
Waxing & waning course	16	28	N/A
Episodic course	10	17	N/A

Table 3Comorbid psychiatric diagnoses ($N=58$)

Disorder	Full (%)	Provisional (%)	Total (%)
Disruptive behavior disorders			
ADHD	22.4	13.8	36.2
Conduct disorder	0	0	0
ODD	12.1	6.9	19
Tic disorders			
Tourette syndrome	1.7	1.7	3.4
Any tic disorder	20.7	6.9	27.6
Anxiety disorders			
Panic disorder	0	1.7	1.7
Specific phobia	17.2	6.9	24.1
GAD	20.7	13.7	34.4
Social phobia	6.9	8.6	15.5
Separation anxiety	13.8	8.6	22.4
Mood disorders			
Major depression	1.7	1.7	3.4
Dysthymia	1.7	3.4	5.1
Mean number of comorbid conditions	1.46	.93	1.67 ^a

^aThe mean number of full and provisional comorbid conditions does not add up to the total number of comorbid conditions because that would have double counted patients who had multiple comorbidities where some were coded as full and some coded as provisional

Table 4

Types of obsessions

Obsessions	<i>n</i>	%
Aggressive/catastrophic	28	56
Religious/scrupulosity	19	38
Sexual	4	8
Contamination	28	56
Somatic	11	22
Magical/superstitious	7	14
Miscellaneous	13	26
Multiple obsessions	37	76

Table 5

Types of compulsions

Compulsions	<i>n</i>	%
Counting	14	28
Checking	34	68
Ordering/arranging	26	52
Washing	31	62
Repeating	29	58
Rituals involving other people	30	60
Superstitious	2	4
Tapping/rubbing	7	14
Miscellaneous compulsions	26	52
Tic-like compulsions	15	29
Multiple compulsions	48	96
Compulsions only	9	18