

# Parental Experiences of Having a Child with Obsessive-Compulsive Disorder: Associations with Clinical Characteristics and Caregiver Adjustment

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**Abstract** We examined parental experience of having a child with obsessive-compulsive disorder (OCD) in 62 parent–child dyads. Youth with a primary diagnosis of OCD and their parent(s) were administered the CY-BOCS jointly by a trained clinician. Parents completed several measures about their child’s OCD-related impairment and accommodation, emotional and behavioral functioning, parental distress, caregiver stress, and parental experiences of having a child with OCD. Results indicated that parents of children with OCD are considerably distressed about their child’s condition. As expected, negative parental experiences (e.g., anxiety about child’s condition, uncertainty about their future) were directly related to OCD symptom severity and impairment, as well as child

internalizing and externalizing problems, family accommodation of symptoms, and caregiver strain. The presence of emotional resources was negatively related to most outcomes, although some of these relationships did not achieve statistical significance. The presence of internalizing symptoms mediated the relationship between parental experiences and parental distress. Given these findings, addressing parental experiences as part of a family based cognitive-behavioral treatment program for pediatric OCD may help reduce parental distress and improve patient prognosis.

**Keywords** Obsessive-compulsive disorder · Parental experiences · Children · Treatment · Assessment

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## Introduction

Obsessive-compulsive disorder (OCD) affects between 1% and 3% of the general youth population before adulthood (Douglass et al. 1995; Zohar 1999). Contrary to previous beliefs which placed the onset of OCD at early adulthood (Burke et al. 1990), most individuals have an onset during childhood (Pauls et al. 1995; Pinto et al. 2006) and meeting OCD criteria increases the risk for the development of other psychiatric disorders (Geller 2006). Although effective psychological and pharmacological treatments exist (see Abramowitz et al. 2005 for a review), pediatric OCD runs a chronic and impairing course into adulthood if it is not appropriately treated (Piacentini et al. 2003; Pinto et al. 2006), during which time it has been associated with considerable functional impairment (Steketee 1997). Similar to many other childhood psychiatric disorders, pediatric OCD is a condition that often impairs both the affected child and his or her family (Freeman et al. 2003;

Storch et al. 2007a) requiring adaptations in assessment (Merlo et al. 2005) and treatment approaches (e.g., Freeman et al. 2003; Storch et al. 2007b).

Despite the clear impact that OCD can have on family members, the experiences of parents has been surprisingly neglected. Fadden et al. (1987) have noted that family members of people with psychiatric conditions provide care for the affected individual at some expense to their own well-being. Indeed, families of pediatric OCD patients frequently play a critical role in symptom presentation, through their involvement and accommodation of a child's rituals and OCD demands (Lenane et al. 1990; Storch et al. 2007a), typically in unsuccessful (albeit typically well-intentioned) efforts to reduce ritual engagement, distress, and associated impairment.

To date, little has been published about caregivers' experience of having a family member with OCD and even less attention has been given to pediatric OCD patients. A modest literature exists describing the family environment of adults and children with OCD finding more hostile interactions (Chambless et al. 2001; Hibbs et al. 1991) and less positive problem solving and warmth relative to controls (Barrett et al. 2002; Valleni-Basile et al. 1995). Derisley et al. (2005) compared parents of children with OCD, non-OCD anxiety disorders, and healthy controls, finding that parents of youth with OCD and non-OCD anxiety disorders endorsed significantly more global distress on the Brief Symptom Index (Derogatis and Melisaratos 1983) than parents of healthy controls. Specifically, parents of youth with OCD endorsed higher ratings of depression, anxiety, hostility, phobic anxiety, and interpersonal sensitivity relative to parents of healthy controls. Cooper (1996) demonstrated the presence of considerable personal distress (e.g., depression) in the parents and siblings of children with OCD. Among adults, Stengler-Wenzke et al. (2004a, b) used qualitative methodology to describe the distress associated with OCD related stigma, efforts to conceal the diagnosis from others, and efforts to negotiate symptoms (e.g., whether or not to accommodate, how to access treatment). Amir et al. (2000) found that family members of someone with OCD reported more depressive and anxiety symptoms when they accommodated symptoms.

Taken together, these preliminary data suggest that having a loved one with OCD is a distressing experience. However, a number of questions remain to be addressed that may have implications for understanding the impact of OCD, conducting thorough family-based evaluations, and treatment planning. First, the above studies examined general levels of distress in caregivers, but did not assess specific constructs of parental experience. Recent research within the pediatric chronic illness literature suggests several dimensions of parents' experience of having a sick child (Bonner et al. 2006). Specifically, Bonner et al.

(2006) developed the Parent Experience of Chronic Illness, a measure of parent adjustment related to caring for a child with a chronic illness that has four factor analytically derived domains: Guilt and Worry (i.e., concerns about the child's current and future well-being and distress about the parents' role in the illness), Emotional Resources (i.e., resources that parents have available to contend with the illness), Unresolved Sorrow and Anger (i.e., emotions related to having a child with a chronic illness), and Long-term Uncertainty (i.e., concerns about the impact of the illness on the child). In a sample of 149 parents of children with brain tumors, the Guilt and Worry and Unresolved Sorrow and Anger factors were modestly and positively related to parental depressive ( $r_s = .37$  and  $.39$ ) and anxiety symptoms ( $r_s = .36$  and  $.32$ ), while the Emotional Resources factor was modestly and negatively related to depressive and anxiety symptoms ( $r_s = -.30$  and  $-.32$ ). Second, little data have been reported on how the parental experience of having a child with OCD may be related to variables such as caregiver strain and OCD symptom severity. It is conceivable, for example, that as OCD severity increases, concerns about the child's future and associated distress would also increase. Finally, in addition to the contribution of OCD on parental experiences, it is reasonable to expect that certain factors may impact the relationship between having a child with OCD and the parent's experience. In particular, the presence of co-occurring externalizing or internalizing behavior problems may further contribute to parents' experiences by making youth more difficult to manage, and raising uncertainty about the child's future and/or ability to handle stressors. If either or both externalizing or internalizing behavior problems are linked to more negative parental experiences in a mediational manner, adjunctive treatment methods (e.g., behavioral parent-training) may focus on reducing these concerns concurrent with addressing OCD symptoms.

In the present study, we examined parental experience of having a child with OCD. We had three primary research questions. First, do the varied domains of parental experience of having a child with OCD correlate with parental distress and caregiver strain? Second, do these domains also correlate with OCD symptom severity, OCD-related impairment, family accommodation of symptoms, and internalizing and externalizing behavior problems? We hypothesized that the PEGI Guilt and Worry, Unresolved Sorrow and Anger, and Long-term Uncertainty factors would correlate positively with parental distress, caregiver strain, OCD symptom severity, functional impairment, family accommodation, and child internalizing and externalizing behavior problems whereas the PEGI Emotional Resources factor would negatively correlate with the above criterion variables. Third, do co-occurring child internalizing and externalizing behavior problems mediate the

relations among parental experiences and parental distress? We expected that negative parental experiences as assessed by the PEGI Guilt and Worry, Unresolved Sorrow and Anger, and Long-term Uncertainty factors would relate to more severe co-occurring internalizing and externalizing behavior problems, resulting in increased parental distress.

## Method

### Participants

The present sample consisted of 62 children and adolescents (31 females) and their primary caregiving parent/guardian who were being evaluated for treatment of the child's OCD. The mean age of youth was 12.56 years (range = 6–20 years;  $SD = 3.57$ ). Fifty-three mothers, 8 fathers, and 1 caregiving grandparent completed forms. Each participant had a primary diagnosis of OCD made by a licensed psychologist based on a clinical interview lasting 90-min and administration of study measures (e.g., Children's Yale-Brown Obsessive-Compulsive Scale; Scahill et al. 1997). The clinical interview followed a structured format that corresponded to DSM-IV-TR diagnostic criteria for OCD and other diagnoses. Both the primary and comorbid diagnoses were confirmed by the fourth author following a discussion of the participants' presenting condition and records review. Only those participants for whom an OCD diagnosis was made with complete certainty were included. Instances of disagreement for comorbid diagnoses were discussed to arrive at a consensus. In the infrequent instance that agreement was not achieved, the first author made the final determination. Demographic information about the study sample is contained in Table 1.

### Measures

#### *Children's Yale-Brown Obsessive-Compulsive Scale (CY-BOCS)*

Derived from the Yale-Brown Obsessive-Compulsive Scale (Goodman et al. 1989), the CY-BOCS (Scahill et al. 1997) is a clinician-rated inventory designed to measure the presence/absence and severity of OCD symptoms among youth. In the Symptom Checklist, the rater queries for the presence or absence of 62 obsessions and compulsions. Thereafter, the interviewer rates the severity of obsessions and compulsions on five items each (i.e., distress, frequency, interference, symptom control and resistance). Ratings are summed to derive separate Obsession and Compulsion Severity Scores, as well as a Total Score (sum of all items). Widely used, the CY-BOCS has high internal consistency (alphas ranging from .87 to

**Table 1** Demographic characteristics of the study sample

Variable	
Child gender	31 females; 31 males
Child age	$M = 12.56, SD = 3.57$
Child ethnicity/race	
White/Caucasian	51 (82.3%)
African American	2 (3.2%)
Hispanic	6 (9.7%)
Asian	3 (4.8%)
Psychotropic medication	
No medication	16
SRI alone	17
SRI plus augmenting agent	25
Non-SRI medication <sup>a</sup>	4
Comorbidity	
Generalized Anxiety Disorder	7
Depressive Disorders	16
Attention Deficit Hyperactivity Disorder	13
Social phobia	3
Oppositional Defiant Disorder	14
Asperger's Disorder	5
Separation Anxiety Disorder	4
Eating Disorder diagnoses <sup>b</sup>	4
Tourette's Syndrome	7
Bipolar Disorder	4
Body Dysmorphic Disorder	2
Trichotillomania	1

Note: SRI = Serotonin Reuptake Inhibitor

<sup>a</sup> Includes Anorexia and Eating Disorder NOS

<sup>b</sup> Includes three youth taking ADHD specific medications and one child taking an atypical antipsychotic medication alone

.90; Scahill et al. 1997; Storch et al. 2004), good inter-rater reliability (Yucelen et al. 2006), strong convergent and divergent validity (Scahill et al. 1997; Storch et al. 2004), and has been shown to be treatment sensitive (Pediatric Obsessive-Compulsive Disorder Treatment Study Team 2004; Storch et al. 2007b). For the current sample, Cronbach's alpha for the CY-BOCS Total Score was .86.

#### *Parent Experience of Chronic Illness (PECI)*

The PEGI is a 25-item measure designed to examine parental adjustment related to caring for a chronically ill child (Bonner et al. 2006). In the initial validation study in 149 parents of children with brain tumors (Bonner et al. 2006), four subscales were factor analytically derived: Guilt and Worry, Unresolved Sorrow and Anger, Long-term Uncertainty, and Emotional Resources. Internal consistency for the PEGI scales was acceptable ranging from .72 to .89. The PEGI scales also showed significant positive

correlations with scales from established measures of parent adjustment, suggesting adequate construct validity (Bonner et al. 2006). No gender differences in scores were noted between mothers and fathers suggesting its validity for use in both (Bonner et al. 2007). Cronbach's alpha for the Guilt and Worry, Unresolved Sorrow and Anger, Long-term Uncertainty, and Emotional Resources subscales in this sample were between .67 and .87.

#### *Brief Symptom Inventory (BSI)*

The BSI is a 53-item self-report inventory which reflects psychological symptom status. The BSI focuses on nine primary symptom dimensions and three global indices of distress (Derogatis and Melisaratos 1983). Items on the BSI are rated on a five point likert scale, with 0 = "not at all" and 4 = "extremely." Although the BSI has three global distress scales, we only used the Global Severity Index raw score for correlations given that the purpose of this study. The BSI has strong test-retest reliability as well as convergent, discriminant, and construct validity (Boulet and Boss 1991; Derogatis and Melisaratos 1983). Cronbach's alpha for the BSI Global Severity Index in this sample was .95.

#### *Caregiver Strain Questionnaire (CGSQ)*

The CGSQ (Brannan et al. 1997) is a 21-item self-report questionnaire that assesses the extent to which caregivers and families were affected over the previous 6 months by the unique demands of providing care for their child with emotional and/or behavioral disturbances. Items are rated on a five-point likert scale (1 = not at all a problem, 5 = very much a problem). The CGSQ has three factor analytically derived subscales (Brannan et al. 1997): Objective strain (mean of 11 items; i.e., observable negative events due to the youth's problems such as financial strain or disrupted family relations), Subjective externalizing strain (mean of 4 items; i.e., overt negative feelings about the child such as anger, embarrassment, and resentment), and Subjective internalizing strain (mean of six items; i.e., caregiver distress related to the child's problems). Good psychometric properties have been shown for the CGSQ, including good internal consistency and construct validity vis-à-vis correlations in the expected direction with measures of family functioning, parental distress, and child adjustment (Brannan et al. 1997; Brannan and Heflinger 2001; Kang et al. 2005).

#### *Family Accommodation Scale (FAS)*

The FAS (Calvocoressi et al. 1995) is a 13-item index rated on a 5-point scale of the degree to which family members

have accommodated the child's OCD symptoms during the previous month (9 items) and the level of distress/impairment that the family and patient experience due to accommodation or lack thereof (4 items). Although a clinician-rated instrument, we formatted the FAS to be completed via parent-report. The FAS captures multiple domains of accommodation such as the provision of reassurance or objects needed for compulsions, decreased role expectations of the child, and modifying the family environment for the affected youth. The FAS has demonstrated good psychometric properties including adequate internal consistency for the total score (alphas = .76–.80; Calvocoressi et al. 1995; Geffken et al. 2006), and associations with OCD symptom severity and impairment (Storch et al. 2007a). For the current study, Cronbach's alpha for the total score was .91.

#### *Child Obsessive Compulsive Impact Scale—Parent Rated (COIS-P)*

The parent-rated COIS-P (Piacentini and Jaffer 1999) contains 56 items pertaining to OCD-related impairment in several areas of child psychosocial functioning (school activities [16 items], social activities [19 items], and home/family activities [17 items]). An additional four questions assess global impairment related to school, social activities, going places, and home/family activities. The COIS-P has demonstrated good internal consistency, convergent validity (Piacentini et al. 2003), and treatment sensitivity (Piacentini et al. 2002; Storch et al. 2007b). For the current study, Cronbach's alpha for the total score was .96.

#### *Child Behavior Checklist (CBCL)*

The CBCL (Achenbach 1991) is a 118-item parent-rating scale that provides a comprehensive assessment of childhood internalizing and externalizing symptoms over the past 6 months. Parents' rate items on a 3-point scale with the following anchors: 0 = "not true" and 2 = "very true or often true." The CBCL consists of eight subscales (Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior), which make up two composite scales (Externalizing and Internalizing problems). Widely used internationally, the CBCL has well-established psychometric properties (Achenbach 1991). Cronbach's alpha for the Internalizing and Externalizing Behavior scores in the present study were .87 and .90.

Procedure

The university institutional review board granted permission to conduct this study. At their initial treatment evaluation at a university affiliated OCD center, families were invited to participate. Of the 65 families approached, only three families declined participation (consent rate = 95%) due to the child’s unwillingness to provide assent ( $n = 1$ ) or parental desire to not participate in research ( $n = 2$ ). After written consent and assent was obtained, a trained clinician administered the CY-BOCS to parents and children jointly. Together with clinician judgment, parent and child responses were used to determine severity ratings. Training of the clinician was directed by the first author and consisted of the following: an instructional meeting about the nature of OCD, commonly comorbid diagnoses, and the CY-BOCS, observation of five administrations by the first author, and administration of five CY-BOCS under direct observation. Weekly rater meetings were held to discuss participant ratings and promote quality assurance. The CY-BOCS was re-administered to 16 subjects by a second trained clinician to examine inter-rater reliability ( $Kappa = .98$ ). After the CY-BOCS was administered, parents completed relevant study measures. The child was given \$5 compensation for their participation.

Data Analysis

A series of one-sample  $t$ -tests were used to compare data obtained from this study to that of the study by Bonner et al. (2006). To examine the first two primary aims, a series of bivariate correlations was conducted. For the third aim, which examines mediational models, the four-step procedure proposed by Baron and Kenny (1986) was used in the following manner. First, the outcome variable (BSI) was regressed on the predictor variables (PECI factors). Second, the proposed mediator variables (CBCL Internalizing and Externalizing) were regressed onto the predictor variables. Third, the outcome variables were regressed onto the mediators while accounting for the predictor. Finally, the addition of the mediator to the full model reduces the relation between the predictor and criterion.

Results

Comparison to Bonner et al. (2006)

Table 2 presents means and standard deviations. Scores for the PECI Guilt and Worry ( $t(61) = -3.80, p < .001$ ) and Unresolved Sorrow and Anger ( $t(61) = -16.96, p < .001$ ) factors were significantly lower in our sample as compared to Bonner et al. (2006). For the PECI Emotional Resources factor, our participants scored significantly higher than the comparison sample ( $t(61) = 13.35, p < .001$ ). No difference was found for the PECI Long-term Uncertainty factor.

Correlations among Parent Experience Indices and Study Variables

Correlations among the PECI factors and parental distress, caregiver strain, OCD symptom severity, OCD functional impairment, family accommodation, and child internalizing and externalizing problems are presented in Table 3. Positive correlations of moderate magnitude were found between the PECI Guilt and Worry, Unresolved Sorrow and Anger, and Long-term Uncertainty factors and the CGSQ Subjective Internalizing and Objective Strain subscales. The PECI Emotional Resources factor and CGSQ Subjective Internalizing subscale were negatively correlated. The PECI Unresolved Sorrow and Anger and Long-term Uncertainty factors were modestly and positively related to the CGSQ Subjective Externalizing subscale. The PECI Guilt and Worry, Unresolved Sorrow and Anger, Long-term Uncertainty, and Emotional Resource factors were moderately correlated with parental distress. Aside from the PECI Emotional Resources factor, correlations between the PECI factors and OCD symptom severity were modest, ranging between .26 and .35. The PECI Guilt and Worry, Unresolved Sorrow and Anger, and Long-term Uncertainty factors were significantly correlated with family accommodation. A large correlation was found between the PECI Long-term Uncertainty factor and OCD related functional impairment whereas small correlations were found between the PECI Guilt and Worry and Unresolved Sorrow and Anger factors and OCD-related functional impairment. All measures excluding the PECI

**Table 2** Descriptive statistics comparing this sample to that of Bonner et al. (2006)

PECI factor	OCD sample		Bonner sample		<i>t</i> -value	<i>p</i> -value
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Guilt and Worry	1.43	.60	1.72	.77	-3.80	.001
Unresolved Sorrow and Anger	1.27	.66	2.70	.66	-16.96	.001
Long-term Uncertainty	1.59	.94	1.51	.82	.64	.52
Emotional Resources	2.99	.60	1.97	.87	13.35	.001

**Table 3** Correlations among Parental Experience of Child Illness Factors and Caregiver Strain Questionnaire

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.
1. PECE Guilt/Worry	–	.69***	.61***	–.36**	.41**	.57***	.24	.47***	.29*	.40**	.31*	.23	.50***
2. PECE Unresolved Sorrow/Anger		–	.78***	–.51***	.46***	.58***	.31*	.31*	.26*	.27*	.32*	.27*	.30*
3. PECE Long-term Uncertainty			–	–.54***	.53***	.64***	.26*	.23	.35**	.28*	.51*	.35**	.30*
4. PECE Emotional Resources				–	–.22	–.45***	–.24	–.28*	–.22	.01	–.17	–.20	–.25
5. CGSQ Objective Strain					–	.67***	.41**	.44**	.35**	.67**	.57**	.63***	.43**
6. CGSQ Internalizing Strain						–	.53***	.55**	.37**	.43**	.48**	.55***	.56***
7. CGSQ Externalizing Strain							–	.22	.02	.12	.001	.46***	.29*
8. BSI Global Severity Index								–	.22	.38**	.34*	.24	.58***
9. CY-BOCS Total									–	–.30*	.48**	.46***	.41**
10. FAS Total Score										–	.52***	.44***	.38**
11. COIS-P Total Score											–	.47***	.55***
12. CBCL Externalizing												–	.52***
13. CBCL Internalizing													–
<i>M</i>	1.43	1.27	1.59	2.99	30.98	19.69	10.10	.56	26.39	25.97	53.59	16.03	19.17
<i>SD</i>	.60	.66	.94	.60	10.27	5.55	2.86	.48	4.69	12.06	31.99	11.19	10.87

*Note:* *SD* = Standard deviation; 1 = PECE Guilt and Worry factor, 2 = PECE Unresolved Sorrow and Anger factor, 3 = PECE Long-term Uncertainty factor, 4 = Emotional Resources factor, 5 = CGSQ Objective Strain, 6 = CGSQ Internalizing Strain, 7 = CGSQ Externalizing Strain, 8 = Brief Symptom Index, 9 = Children's Yale-Brown Obsessive-Compulsive Scale Total Score, 10 = Family Accommodation Scale Total Score, 11 = Child Obsessive-Compulsive Impact Scale-Parent Version, 12 = Child Behavior Checklist Externalizing Scale, 13 = Child Behavior Checklist Internalizing Scale

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

Guilt and Worry and Emotional Resources factors were significantly correlated with child externalizing behavior problems ( $r_s = .27-.47$ ). Finally, only the PECE Emotional Resources factor was not significantly correlated with child internalizing behavior problems ( $r_s = .29-.58$ ).

**Internalizing Problems as a Mediator of Parental Experience and Parental Distress**

*PECE Guilt and Worry Factor*

The first step in the mediational analysis revealed that the PECE Guilt and Worry factor ( $B = .47, p < .001$ ) was related to the BSI Global Severity Index. In the second step, the CBCL Internalizing Scale was significantly related to the PECE Guilt and Worry factor ( $B = .50, p < .001$ ). For the third step, the CBCL Internalizing Scale was related to the BSI Global Severity Index ( $B = .58, p < .001$ ). Finally, the fourth step demonstrated that the CBCL Internalizing Scale score ( $B = .46, p < .001$ ) mediated the relationship between the PECE Guilt and Worry factor ( $B = .24, ns$ ) and BSI total score ( $F(2, 55) = 16.76, p < .001$ ) and accounted for 38% of the variance. Table 4 presents the final model.

*PECE Sorrow and Anger Factor*

The PECE Sorrow and Anger factor was significantly related to the BSI Global Severity Index ( $B = .31, p < .05$ ) and the CBCL Internalizing Scale ( $B = .30, p < .05$ ), thus satisfying the first two steps of the mediational analysis. On the third step, the BSI Global Severity Index and the CBCL Internalizing Scale were significantly related ( $B = .58, p < .001$ ). For the final step, the CBCL Internalizing Scale ( $B = .54, p < .001$ ) score mediated the relationship between the PECE Sorrow and Anger factor ( $B = .13, ns$ ) and BSI Global Severity Index ( $F(2, 55) = 14.74, p < .001$ ), accounting for 35% of the variance. See Table 5 for the final model.

**Table 4** Mediation regression analysis predicting parental distress: internalizing problems mediating parental experience of Guilt and Worry and Parental Distress

Step	Variables	$R^2$	$\Delta R^2$	$F$	$\beta$
1	CBCL Internalizing	.34	.34	28.16*	.46*
2	PECE Guilt and Worry	.38	.04	16.76*	.24

All standardized regression coefficients are from the final block of the equation

\*  $p < .001$

**Table 5** Mediation regression analysis predicting parental distress: internalizing problems mediating parental experience of Sorrow and Anger and Parental Distress

Step	Variables	$R^2$	$\Delta R^2$	$F$	$\beta$
1	CBCL Internalizing	.34	.34	28.16*	.54*
2	PECE Sorrow and Anger	.35	.01	14.74*	.13

All standardized regression coefficients are from the final block of the equation

\*  $p < .001$

*PECE Long-term Uncertainty Factor*

The relationship between the PECE Long-term Uncertainty factor and the BSI Global Severity Index was not significant. Therefore, no mediational relationship could be tested.

*PECE Emotional Resources Factor*

The first two steps of the test for mediation revealed that the PECE Emotional Resources factor was related to the BSI Global Severity Index ( $B = -.28, p < .01$ ) and the CBCL Internalizing Scale ( $B = -.25, p < .05$ ). The BSI Global Severity Index and the CBCL Internalizing Scale were related ( $B = .58, p < .001$ ). The final model demonstrated that the CBCL Internalizing Scale ( $B = .54, p < .001$ ) mediated the relationship between the PECE Emotional Resources factor ( $B = -.14, ns$ ) and the BSI Global Severity Index accounting for 35% of the variance. Table 6 presents the final model.

**Externalizing Problems as a Mediator of Parental Experience Parental Distress**

Tests of mediation revealed that the PECE Guilt and Worry factor alone was significantly related to the BSI Global Severity Index ( $B = .52, p < .01$ ). However, the PECE Guilt and Worry factor was not related to CBCL Externalizing Scale; thus it is not possible to examine mediation.

**Table 6** Mediation regression analysis predicting parental distress: internalizing problems mediating parental experience of Emotional Resources and Parental Distress

Step	Variables	$R^2$	$\Delta R^2$	$F$	$\beta$
1	CBCL Internalizing	.34	.34	28.16*	.54*
2	PECE Emotional Resources	.35	.02	14.99*	-.14

All standardized regression coefficients are from the final block of the equation

\*  $p < .001$

## Discussion

Despite the considerable familial disruption and role of parents in the clinical presentation of pediatric OCD, to date, little attention has been given to parents' experiences. In the present study, we addressed this issue by examining parents' experiences of having a child with OCD and its relationship to symptom severity, impairment, parental distress, family accommodation, caregiver strain, and co-occurring internalizing and externalizing behavior problems. In general, our results suggest that parents of youth with OCD experience lower levels of Guilt and Worry, and Unresolved Sorrow and Anger than parents of youth with a brain tumor, a finding that is not surprising given the life-threatening nature of the latter condition. Interestingly, scores on the Long-term Uncertainty factor were comparable to that of Bonner et al. (2006) suggesting that parents are concerned about their child's ability to function in an age-appropriate manner during varied developmental epochs. This is consistent with our clinical experiences as parents often question how their child will be able to pursue educational opportunities or maintain a job or relationships without successful treatment. Interestingly, when one considers that the vast majority of OCD patients do not receive first-line cognitive-behavioral treatment (Blanco et al. 2006), it is possible that such findings are impacted, at least in part, by the struggle to locate effective treatment.

Consistent with Bonner et al. (2006), the three 'distress' domains of parental experience (Guilt and Worry, Unresolved Sorrow and Anger, and Long-term Uncertainty) were positively associated with parental distress and caregiver strain. Some of these parental experiences reflect serious concerns confronting parents (e.g., I worry that my child's illness will worsen/return) that may be a cause for chronic anxiety about the child's functioning or require considerable efforts and resources to maintain current levels of functioning (e.g., finances, frequent treatment appointments; Kazak et al. 2004). The PECE Emotional Resources factor, a measure of parents' perceived adaptive resources, was negatively associated with parental distress and caregiver strain, a finding that is also consistent with the pediatric chronic illness literature (e.g., Hastings et al. 2005; Kazak et al. 2004). It is not surprising that the presence of positive support may buffer against parental distress by sharing caregiving tasks with family members, limiting the impact of stressors, and serving as an emotional outlet during difficult times. Overall, these results suggest that, in addition to working directly with the affected child, distressed parents may benefit from adjunctive treatment targeting their experiences of caring for their child and/or their personal distress. More specifically, parents may benefit from efforts aimed at increasing

the availability of psychosocial resources, as well as more traditional approaches at targeting distress. The latter point is particularly important given the negative impact that parental psychopathology can have on treatment course and functioning (e.g., reduce homework compliance or session attendance; Crawford and Manassis 2001).

As expected, the PECE 'distress' scales (Guilt and Worry, Unresolved Sorrow and Anger, and Long-term Uncertainty) were positively related to OCD symptom severity, OCD-related impairment, and family accommodation of symptoms. Intuitively, increased OCD symptom severity and OCD-related impairment may contribute to parental distress by virtue of increasing parental burden and responsibility (e.g., managing symptoms, increased frequency of treatment appointments), anxiety about their child's future, and parental doubts about their ability to effectively manage their child's OCD. Furthermore, efforts to accommodate a child's OCD symptoms likely contribute to parents' experience of caring for a child with OCD by increasing the frequency of negative interactions and serving as a daily reminder of their child's limitations. In the context of recent data indicating that decreases in family accommodation during treatment predicts treatment outcome (Merlo et al. in press), these results suggest that it is important to target family accommodation in pediatric OCD to also alleviate negative parental experiences and distress, as well as family impairment.

The presence of co-occurring externalizing and internalizing behavior problems were associated in the expected directions with parents' experiences of caring for a child with OCD. Youth with OCD who experience higher levels of internalizing or externalizing behavior problems may be more difficult to manage by virtue of interference with family activities and cohesion (Klassen et al. 2004). Adjunctive treatment methods such as behavioral parent training or pharmacological management may be needed to address these problems concurrent to addressing OCD symptoms.

The final study aim examining if co-occurring internalizing and externalizing behavior problems mediated the relations among parental experiences and parental distress was partially confirmed. Analyses revealed that child internalizing (but not externalizing) symptoms mediated the relationships between the PECE Guilt and Worry and Unresolved Sorrow and Anger factors, and parental distress. Directly targeting co-occurring internalizing symptoms may reduce parental distress by reducing the emotional and tangible demands on the parents. For example, reductions in child internalizing symptoms may improve home (e.g., bedtime issues such as fears of the dark) or school (e.g., difficulty completing homework independently) functioning thereby reducing parental burden. Child internalizing symptoms also mediated the



relationship between PEGI Emotional Resources and parental distress. These findings suggest that child internalizing problems coupled with low perceived emotional resources on the part of parents contributes to parental distress, a finding that lends support to the argument that distressed parents may benefit from adjunctive strategies to improve coping abilities and access to psychosocial resources.

Although these data are informative, several limitations should be considered when interpreting the results. First, with the exception of the CY-BOCS, we relied solely on parent-rated instruments. The lack of method variance might inflate observed relationships between variables. Observational assessments and clinician-rated measures of parent adjustment should be incorporated into future research. Second, speculations regarding directions of causal effects must be supported by future research employing prospective designs. Third, although mothers often assume the primary caretaking role, they were disproportionately represented in the sample which may limit the generalizability of these data to fathers. Fourth, Caucasians were disproportionately represented in the sample, so caution should be exercised in generalizing the findings to other ethnicities/races. Finally, other factors not investigated in this study may be relevant to understanding parental experiences (e.g., duration of illness, family factors such as socioeconomic status). Within these limitations, these data support the notion that having a child with OCD is a distressing experience. Parents with greater perceived emotional resources, however, appeared to be at least somewhat buffered from the negative effects of caring for a child with OCD. These findings are suggestive of the need to address parental experiences as part of an overall family-based treatment approach to managing pediatric OCD. To that end, the PEGI could be used as a tool to screen for parent adjustment in OCD and other psychiatric disorders.

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## References

- Abramowitz, J. S., Whiteside, S. P., & Deacon, B. J. (2005). The effectiveness of treatment for pediatric Obsessive-Compulsive Disorder: A meta-analysis. *Behavior Therapy, 36*, 55–63. doi:10.1016/S0005-7894(05)80054-1.
- Achenbach, T. M. (1991). *Manual for the child behavior checklist/4–18 and 1991 profile*. Burlington: University of Vermont, Department of Psychiatry.
- Amir, N., Freshman, M., & Foa, E. B. (2000). Family distress and involvement in relatives of obsessive-compulsive disorder patients. *Journal of Anxiety Disorders, 14*, 209–217. doi:10.1016/S0887-6185(99)00032-8.
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173–1182. doi:10.1037/0022-3514.51.6.1173.
- Barrett, P., Shortt, A., & Healy, L. (2002). Do parent and child behaviours differentiate families whose children have obsessive-compulsive disorder from other clinic and non-clinic families? *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 43*, 597–607. doi:10.1111/1469-7610.00049.
- Blanco, C., Olfson, M., Stein, D. J., Simpson, H. B., Gameroff, M. J., & Narrow, W. H. (2006). Treatment of obsessive-compulsive disorder by U.S. psychiatrists. *The Journal of Clinical Psychiatry, 67*, 946–951.
- Bonner, M. J., Hardy, K. K., Guill, A. B., McLaughlin, C., Schweitzer, H., & Carter, K. (2006). Development and validation of the parent experience of child illness. *Journal of Pediatric Psychology, 31*, 310–321. doi:10.1093/jpepsy/jsj034.
- Bonner, M. J., Hardy, K. K., Willard, V. W., & Hutchinson, K. C. (2007). Psychosocial functioning of fathers as primary caregivers of pediatric oncology patients. *Journal of Pediatric Psychology, 32*, 851–856. doi:10.1093/jpepsy/jsm011.
- Boulet, J., & Boss, M. V. (1991). Reliability and validity of the Brief Symptom Inventory. *Psychological Assessment, 3*, 433–437. doi:10.1037/1040-3590.3.3.433.
- Brannan, A. M., & Heflinger, C. A. (2001). Distinguishing caregiver strain from psychological distress: Modeling the relationships among child, family, and caregiver variables. *Journal of Child and Family Studies, 10*, 405–418. doi:10.1023/A:1016705306848.
- Brannan, A. M., Heflinger, C. A., & Bickman, L. (1997). The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional problems. *Journal of Emotional and Behavioral Disorders, 5*, 212–222.
- Burke, C., Burke, J. D., Jr., Regier, D. A., & Rae, D. S. (1990). Age at onset of selected mental disorders in five community populations. *Archives of General Psychiatry, 47*, 511–518.
- Calvocoressi, L., Lewis, B., Harris, M., Trufan, S. J., Goodman, W. K., McDougle, C. J., et al. (1995). Family accommodation in obsessive compulsive disorder. *The American Journal of Psychiatry, 152*, 441–443.
- Chambless, D. L., Bryan, A. D., Aiken, L. S., Steketee, G., & Hooley, J. M. (2001). Predicting expressed emotion: A study with families of obsessive-compulsive and agoraphobic outpatients. *Journal of Family Psychology, 15*, 225–240. doi:10.1037/0893-3200.15.2.225.
- Cooper, M. (1996). Obsessive compulsive disorder: Effects on family members. *The American Journal of Orthopsychiatry, 66*, 296–304. doi:10.1037/h0080180.
- Crawford, M. A., & Manassis, K. (2001). Familial predictors of treatment outcome in childhood anxiety disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*, 1182–1189. doi:10.1097/00004583-200110000-00012.
- Derisley, J., Libby, S., Clark, S., & Reynolds, S. (2005). Mental health, coping and family-functioning in parents of young people with obsessive-compulsive disorder and with anxiety disorders. *The British Journal of Clinical Psychology, 44*, 439–444. doi:10.1348/014466505X29152.
- Derogatis, L. R., & Melisaratos, N. (1983). The Brief Symptom Inventory: An introductory report. *Psychological Medicine, 13*, 595–605.
- Douglass, H. M., Moffitt, T. E., Dar, R., McGee, R., & Silva, P. (1995). Obsessive compulsive disorder in a birth cohort of 18-year-olds: Prevalence and predictors. *Journal of the American*

- Academy of Child and Adolescent Psychiatry*, 34, 1424–1431. doi:10.1097/00004583-199511000-00008.
- Fadden, G., Bebbington, P., & Kuipers, L. (1987). The burden of care: The impact of functional psychiatric illness on the patient's family. *The British Journal of Psychiatry*, 150, 285–292.
- Freeman, J. B., Garcia, A. M., Fucci, C., Karitani, M., Miller, L., & Leonard, H. L. (2003). Family-based treatment of early-onset obsessive-compulsive disorder. *Journal of Child Adolescent Psychopharmacology*, 13S1, S71–S80.
- Geffken, G. R., Storch, E. A., Duke, D. C., Monaco, L., Lewin, A. B., & Goodman, W. K. (2006). Hope and coping in family members of patients with obsessive-compulsive disorder. *Journal of Anxiety Disorders*, 20, 614–629. doi:10.1016/j.janxdis.2005.07.001.
- Geller, D. A. (2006). Obsessive-compulsive and spectrum disorders in children and adolescents. *The Psychiatric Clinics of North America*, 29, 353–370. doi:10.1016/j.psc.2006.02.012.
- Goodman, W. K., Price, L. H., Rasmussen, S. A., Mazure, C., et al. (1989). The Yale-Brown Obsessive Compulsive Scale: Validity. *Archives of General Psychiatry*, 46, 1006–1011.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9, 377–391. doi:10.1177/1362361305056078.
- Hibbs, E. D., Hamburger, S. D., Lenane, M., Rapoport, J. L., Kruesi, M. J., Keyser, C. S., et al. (1991). Determinants of expressed emotion in families of disturbed and normal children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 32, 757–770. doi:10.1111/j.1469-7610.1991.tb01900.x.
- Kang, E. J., Brannan, A. M., & Heflinger, C. A. (2005). Racial differences in responses to the Caregiver Strain Questionnaire. *Journal of Child and Family Studies*, 14, 43–56. doi:10.1007/s10826-005-1112-1.
- Kazak, A. E., McClure, K. S., Alderfer, M. A., Hwang, W., Crump, T. A., Le, L. T., et al. (2004). Cancer-related parental beliefs: The Family Illness Beliefs Inventory. *Journal of Pediatric Psychology*, 29, 531–542. doi:10.1093/jpepsy/jsh055.
- Klassen, A. F., Miller, A., & Fine, S. (2004). Health-related quality of life in children and adolescents who have a diagnosis of attention-deficit/hyperactivity disorder. *Pediatrics*, 114, e541–e547. doi:10.1542/peds.2004-0844.
- Lenane, M. C., Swedo, S. E., Leonard, H. L., Pauls, D., Sceery, W., & Rapoport, J. L. (1990). Psychiatric disorders in first degree relatives of children and adolescents with obsessive compulsive disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 407–412. doi:10.1097/00004583-199005000-00012.
- Merlo, L. J., Lehmkuhl, H., Geffken, G. R., & Storch, E. A. (in press). Decrease in family accommodation is associated with improved cognitive-behavioral therapy outcome in pediatric obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology*.
- Merlo, L. J., Storch, E. A., Murphy, T. K., & Geffken, G. R. (2005). Assessment of pediatric OCD: A critical review of current methodology. *Child Psychiatry and Human Development*, 36, 195–214. doi:10.1007/s10578-005-4079-7.
- Pauls, D. L., I. I., Alsobrook, J. P., Goodman, W., Rasmussen, S., & Leckman, J. F. (1995). A family study of obsessive-compulsive disorder. *The American Journal of Psychiatry*, 152, 76–84.
- Pediatric Obsessive-Compulsive Disorder Treatment Study Team. (2004). Cognitive-behavioral therapy, sertraline, and their combination for children and adolescents with obsessive-compulsive disorder: The Pediatric Obsessive-Compulsive Disorder Treatment Study Randomized Controlled Trial. *Journal of the American Medical Association*, 292, 1969–1976. doi:10.1001/jama.292.16.1969.
- Piacentini, J., Bergman, R. L., Jacobs, C., McCracken, J. T., & Kretschman, J. (2002). Open trial of cognitive behavior therapy for childhood obsessive-compulsive disorder. *Journal of Anxiety Disorders*, 16, 207–219. doi:10.1016/S0887-6185(02)00096-8.
- Piacentini, J., Bergman, R. L., Keller, M., & McCracken, J. (2003). Functional impairment in children and adolescents with obsessive-compulsive disorder. *Journal of Child and Adolescent Psychopharmacology*, 13S-1, S61–S69.
- Piacentini, J. C., & Jaffer, M. (1999). *Measuring functional impairment in youngsters with OCD: Manual for the Child OCD Impact Scale (COIS)*. Los Angeles: UCLA Department of Psychiatry.
- Pinto, A., Mancebo, M. C., Eisen, J. L., Pagano, M. E., & Rasmussen, S. A. (2006). The Brown Longitudinal Obsessive Compulsive Study: Clinical features and symptoms of the sample at intake. *The Journal of Clinical Psychiatry*, 67, 703–711.
- Scahill, L., Riddle, M. A., McSwiggin-Hardin, M., Ort, S. I., King, R. A., Goodman, W. K., et al. (1997). Children's Yale-Brown Obsessive Compulsive Scale: Reliability and validity. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 844–852. doi:10.1097/00004583-199706000-00023.
- Steketee, G. (1997). Disability and family burden in obsessive-compulsive disorder. *Canadian Journal of Psychiatry*, 42, 919–928.
- Stengler-Wenzke, K., Trosbach, J., Dietrich, S., & Angermeyer, M. C. (2004a). Coping strategies used by the relatives of people with obsessive-compulsive disorder. *Journal of Advanced Nursing*, 48, 35–42. doi:10.1111/j.1365-2648.2004.03166.x.
- Stengler-Wenzke, K., Trosbach, J., Dietrich, S., & Angermeyer, M. C. (2004b). Experience of stigmatization by relatives of patients with obsessive compulsive disorder. *Archives of Psychiatric Nursing*, 18, 88–96. doi:10.1016/j.apnu.2004.03.004.
- Storch, E. A., Murphy, T. K., Geffken, G. R., Soto, O., Sajid, M., Allen, P., et al. (2004). Psychometric evaluation of the Children's Yale-Brown Obsessive Compulsive Scale. *Psychiatry Research*, 129, 91–98. doi:10.1016/j.psychres.2004.06.009.
- Storch, E. A., Geffken, G. R., Merlo, L. J., Jacob, M. L., Murphy, T. K., Goodman, W. K., et al. (2007a). Family accommodation in pediatric obsessive-compulsive disorder. *Journal of Clinical Child and Adolescent Psychology*, 36, 207–216.
- Storch, E. A., Geffken, G. R., Merlo, L. J., Mann, G., Duke, D., Munson, M., et al. (2007b). Cognitive-Behavioral therapy for pediatric obsessive-compulsive disorder: Comparison of intensive and weekly approaches. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46, 469–478. doi:10.1097/chi.0b013e31803062e7.
- Valleni-Basile, L. A., Garrison, C. Z., Jackson, K. L., Waller, J. L., McKeown, R. E., Addy, C. L., et al. (1995). Family and psychosocial predictors of obsessive-compulsive disorder in a community sample of young adolescents. *Journal of Child and Family Studies*, 4, 193–206. doi:10.1007/BF02234095.
- Yucelen, A. G., Rodopman-Arman, A., Topcuoglu, V., Yazgan, M. Y., & Fisek, G. (2006). Interrater reliability and clinical efficacy of Children's Yale-Brown Obsessive-Compulsive Scale in an outpatient setting. *Comprehensive Psychiatry*, 47, 48–53. doi:10.1016/j.comppsy.2005.04.005.
- Zohar, A. H. (1999). The epidemiology of obsessive-compulsive disorder in children and adolescents. *Child and Adolescent Psychiatric Clinics of North America*, 8, 445–460.

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