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ORIGINAL PAPER

Quality of life in children and adolescents with obsessive-compulsive disorder: base rates, parent–child agreement, and clinical correlates

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Abstract The presence of obsessive-compulsive disorder (OCD) has been linked to decreased quality of life (QoL) among adults, yet little is known about the impact of OCD on QoL in pediatric patients. Sixty-two youth with OCD and their parent(s) were administered the Children's Yale-Brown Obsessive Compulsive Scale following a clinical interview. Children completed the Pediatric Quality of Life Inventory and parents completed the Pediatric Quality of Life Parent Proxy Inventory and Child Behavior Checklist. QoL scores for OCD patients were significantly lower than for healthy controls, but similar to QoL in a general psychiatric sample on the majority of domains. Parent–child agreement on QoL was moderate to strong across age groups. Results indicate that, in youth with OCD, QoL is reduced relative to healthy controls, related to OCD symptom severity per parent-report, and are strongly predicted by the presence of comorbid externalizing and internalizing symptoms.

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Introduction

Obsessive-compulsive disorder (OCD) is a prevalent childhood illness affecting approximately 1–3% of youth [42] that has been associated with substantial impairment in family, social, and academic realms [20]. Symptomatically, pediatric OCD patients experience obsessions and/or compulsions that are time consuming, distressing, and interfere with daily functioning. In addition to OCD, up to 75% of these patients also meet criteria for one or more comorbid conditions, with the most frequent being attention-deficit/hyperactivity disorder (ADHD), disruptive behavior disorders, depressive disorders, and other anxiety disorders [10, 13, 25]. In addition to psychiatric comorbidity, many youth with OCD experience problematic peer relations, academic difficulties, and participate in fewer recreational activities than non-affected peers [35, 38].

Given the considerable functional impairment related to OCD and comorbid diagnoses, it is not surprising that health-related quality of life (QoL) may be impacted. Functional impairment can be defined as the inability to perform routine and age-appropriate tasks in the domains of school, home, and social activities [14, 31]. QoL, in comparison, can be defined as "a patient's perceptions of the impact of disease and treatment functioning in a variety of dimensions including physical, mental, and social domains" [39]. While QoL and functional impairments are related concepts, they are not the same thing [32], which is why it is surprising that the impact of OCD on QoL in a pediatric population has yet to be reported despite anecdotal evidence that QoL may be lower than in non-clinical controls. For example, clinical experiences of the researchers suggest that children with OCD report elevated levels of somatic and depressive symptoms, have difficulty participating in age-appropriate peer activities due to anxiety and ritual engagement, and often are the center of problematic family relations.

Examining QoL in pediatric OCD patients has relevance for both assessment and treatment. In assessment, QoL provides a subjective estimate of overall functioning across multiple domains. Targeting specific symptoms without attending to QoL may result in the confounding of assessment data as the patient may have reduced symptoms that do not translate into improved day-to-day functioning. In treatment, recent attention has focused on the external validity of clinical trial results–do gains seen on standardized clinical measures correspond to clinically meaningful changes in real-world functioning [36]? Evidence in adults with OCD suggests that both cognitive-behavioral therapy and pharmacotherapy are associated with improved QoL following treatment [8, 19], but this has yet to be studied in youth. Although the present study will not directly examine change in QoL following treatment, it can provide information about the baseline level of QoL in pediatric OCD patients.

Although little QoL data exists in pediatric OCD patients, a modest literature shows that adult OCD patients experience lower QoL relative to healthy controls [6, 26, 30], psychiatric patients with schizophrenia [30], heroin addiction [6] and clinical depression [6]. Studies have also demonstrated inverse relations between QoL and OCD symptom severity [9, 17, 18, 22, 26, 29], and a direct association with insight [9].

In non-OCD pediatric psychiatric populations, QoL has been shown to be significantly decreased. In youth with a chronic tic disorder [33], QoL was lower compared to healthy controls but higher than a general psychiatric sample, with child QoL ratings inversely correlated to tic severity. Quality of life has also been inversely related to symptom severity in youth with depression [41], ADHD [16, 23], bipolar disorder [21], and a sample of youth with varied psychiatric diagnoses [4]. Underlying these relationships is the notion that disease specific symptoms contribute to daily life burdens and disability across physical, mental, and social domains [40].

Although documenting the relationship between symptom severity and QoL is useful and a goal of the present study, it does not explain when QoL may be impacted. One variable that may moderate the relationship between symptom severity/impairment and QoL is comorbidity. In pediatric OCD, there has been little attention to QoL; thus, the use of psychiatric-related impairment as a proxy for conceptualizing the impact of comorbidity must be used. ADHD and disruptive behavior comorbidities have been the most frequently studied in relation to their additional contribution to psychosocial disability, finding that impairments were greater in youth with OCD and comorbid ADHD relative to healthy controls and youth with OCD without ADHD [35]. Similarly, comorbid ADHD in youth with OCD was associated with greater functional impairment [11, 12]. Carter et al. [7] found comparable results to those of Sukhodolsky et al. [35] and Geller et al. [11, 12] in youth with Tourette's Syndrome and ADHD. Storch et al. [31] found that tic severity was significantly associated with parent-rated QoL for children with below average externalizing symptoms but not for children with above average externalizing symptoms. Although little has been reported on the additional impact of internalizing disorders in pediatric OCD, evidence from adults with OCD suggests that depressed patients show more severe functional disability relative to non-depressed patients [1, 24, 37]. Such findings suggest that those youth with comorbid conditions may experience greater impairments in QoL and further consideration in treatment planning (e.g., adjunctive pharmacotherapy). While these studies are informative in understanding how comorbidity may impact QoL, with the exception of the Storch et al. [31] study, they focus on the role of comorbidity on functional impairment, not QoL.

The present study examines QoL in pediatric OCD patients and had three specific aims. The first aim was to examine the associations between OCD symptom severity and QoL scores. Based on previous research, it was expected that OCD symptom severity would be negatively related to both child and parent-proxy reports of QoL. Second, the researchers wanted to examine parent–child agreement in QoL and determine whether agreement differed by age. Based on prior reports in psychiatric samples, it was hypothesized that there would be a strong positive association between parent and child ratings, and that this association would be significantly stronger in children versus adolescents. Last, the extent to which comorbid internalizing and externalizing symptoms contributed to the prediction of QoL was examined. The prediction was that OCD severity and co-occurring internalizing and externalizing behavior problems would interact in predicting QoL, such that those with additional problems would report lower QoL.

Method

Participants

Sixty-two youth (31 females) diagnosed with OCD and presenting for an initial treatment evaluation at an OCD specialty clinic within Shands Hospital at the University of Florida between September 2006 and July 2007 participated in this study. Participants' mean age was 12.56 years (SD = 3.57; range 8–17 years) and the majority were Caucasian (82%) followed by 9.7% Hispanic American, 4.8% Asian American and 3.2% African American. Fifty-three mothers, eight fathers, and one caregiving grandmother completed relevant parent forms. OCD and comorbid diagnoses were made by a licensed clinical psychologist (E. A. Storch) according to the DSM-IV-TR [3]. Primary and comorbid diagnoses were determined through a 90-min semi-structured clinical interview with the participant and his/her caregiver(s) that focused on the child's primary clinical presentation (obsessive-compulsive disorder) with follow-up questions concerning secondary diagnoses or difficulties (e.g., depressive symptoms) as needed. Following this, information from the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) [28] and other measures were reviewed. Finally, Dr. Storch, a clinical psychologist, discussed his clinical impressions and measurement data with Dr. Murphy, a child psychiatrist, to determine consensus diagnoses. There were no instances of disagreement for the primary diagnosis of OCD. In the rare instance that there was a disagreement about a comorbid diagnosis, the disagreement was resolved via discussion and examination of clinical data. Comorbid diagnoses included disruptive behavior disorders ($n = 14$), depressive disorders ($n = 16$), ADHD ($n = 13$), Generalized Anxiety Disorder ($n = 7$), Tourette's Syndrome ($n = 7$), Asperger's Syndrome ($n = 5$), Separation Anxiety Disorder ($n = 4$), Bipolar Disorder ($n = 4$), Eating Disorders ($n = 4$), Social Phobia ($n = 3$), Body Dysmorphic Disorder ($n = 2$), and Trichotillomania ($n = 1$).

Measures

Children's Yale-Brown Obsessive Compulsive Scale

Administered by a trained clinician, the widely used CY-BOCS Severity Scale [28] consists of ten items measuring obsession and compulsion severity over a 1-week interval. Separate Obsession and Compulsion Severity Scores are derived by summing the applicable five items; a Total Score is derived by summing all items. Excellent psychometric properties in support of the CY-BOCS have been shown [28, 34].

Pediatric Quality of Life Inventory

The Pediatric Quality of Life Inventory version 4.0 [40] consists of parallel child (PedsQL) and parent-proxy (PedsQL Parent Proxy) measures of youth's QoL. Each of the 23 items is rated on a 5-point scale with higher scores corresponding to better QoL. Four factor analytically derived scales are embedded within the PedsQL: (a) physical functioning (eight items); (b) emotional functioning (five items); (c) social functioning (five items); and (d) school functioning (five items). These scales are combined to yield physical (equivalent to the physical functioning domain), psychosocial (sum of emotional, social, and school functioning domains), and total health scales (all four domains). Extensive psychometric data support the validity and reliability of the PedsQL and PedsQL Parent Proxy across multiple clinical presentations [5, 39].

Child Behavior Checklist

The Child Behavior Checklist (CBCL) [2] is a parent completed index assessing the frequency of 118 emotional and behavioral symptoms. Each item is rated on a 0-1-2 scale for the degree to which that behavior is true for their child. Widely used, the CBCL has strong psychometric properties across a variety of clinical and non-clinical populations [2]. The Internalizing and Externalizing Scales were used in this study.

Procedures

All study procedures were approved by the University of Florida Institutional Review Board. After explaining the purpose of the study to the participating child and his/her parent(s), written parental consent and child assent was obtained. Youth were compensated \$5.00 for their participation. After obtaining consent/assent, a trained research assistant (RA) administered the CY-BOCS to the child and parent jointly in a private office. The second author trained the RA, which consisted of an instructional meeting about the CY-BOCS, five practice interviews, and five observed interviews. Interrater reliability was high for 16 CY-BOCS that were jointly administered by the RA and second author (Intraclass correlation coefficient = 0.98). Following the CY-BOCS administration, the RA provided instructions for completing child- and parent-report measures.

Results

Using a 2 (gender) × 2 (age group 6–11 and 12–20 years) analysis of variance (ANOVA), QoL scores for males ($M = 71.72$, SD 17.21) were significantly higher than for females ($M = 62.03$, SD 15.02) on the PedsQL total score [$F(1, 61) = 5.18$, $P = 0.03$], but not on PedsQL Parent-Proxy total score (male $M = 65.71$ vs. female $M = 60.25$) [$F(1, 61) = 1.47$, $P = 0.23$]. No significant

Table 1 Correlations between PedsQL child self-report and parent-report

	Ages 6–11 ($n = 25$)			Ages 12–17 ($n = 37$)		
	r	Child-rating M ± SD	Parent-rating M ± SD	*r*	Adolescent-rating M ± SD	Parent-rating M ± SD
Total score	0.62*	67.46 ± 15.39	65.29 ± 15.42	0.67*	66.49 ± 17.80	61.42 ± 19.22
Physical health	0.49	77.34 ± 18.11	78.56 ± 18.14	0.46	75.95 ± 21.11	73.40 ± 22.32
Psychosocial health	0.62*	64.17 ± 16.12	60.87 ± 16.64	0.69*	63.33 ± 18.17	57.43 ± 20.01
Emotional functioning	0.73*	55.62 ± 25.38	52.60 ± 26.11	0.73*	57.50 ± 23.56	50.41 ± 20.96
Social functioning	0.42	75.21 ± 15.91	69.80 ± 22.61	0.58*	74.58 ± 21.69	69.59 ± 22.31
School functioning	0.49	61.67 ± 19.70	60.20 ± 22.24	0.76*	57.92 ± 22.66	52.30 ± 29.24

* $P < 0.004$

differences were found between age groups on either PedsQL or PedsQL Parent-Proxy total scores, nor were there any significant gender or age interactions. Differences on the PedsQL and PedsQL Parent-Proxy subscale scores were examined using a 2 (gender) × 2 (age group) multivariate analysis of variance, with no significant age or gender differences observed.

Parent–child agreement in quality of life scores

To examine the relationship between parent and child QoL ratings, Pearson product-moment correlations were computed separately for youth ages 8–11 and 12–17 years (see Table 1). Using the Bonnferoni correction, alpha was again set at 0.004 (0.05/12). For youth ages 8–11 years, strong, positive correlations were found between parent and child reports on the PedsQL/PedsQL Parent-Proxy total score, psychosocial health, emotional functioning, and school functioning. For youth ages 12–17 years, significant correlations were found on all of the PedsQL domains.

Relationship between QoL, symptom severity, and internalizing-externalizing problems

Pearson product-moment correlations were calculated to examine the relations between QoL as measured by the PedsQL and PedsQL Parent-Proxy, OCD symptom severity as measured by the CY-BOCS, and internalizing and externalizing problems as measured by the CBCL (see Table 2). The majority of PedsQL scores, both child- and parent-reported, were moderately correlated to measures of OCD symptom severity, internalizing, and externalizing problems. Non-significant relationships were found between the PedsQL physical health subscale and OCD symptom severity, and PedsQL physical health and social functioning subscales and externalizing behavior problems.

Interaction of internalizing and externalizing symptoms with OCD severity as a predictor of PedsQL scores

A final goal of this study was to investigate the interaction of internalizing and externalizing symptoms with OCD

Table 2 Pearson correlation coefficients of the PedsQL with CY-BOCS and CBCL Scores

	CY-BOCS	CBCL externalizing	CBCL internalizing	CBCL total
Child self-report				
Total Score	0.34**	0.35**	0.65***	0.56***
Physical health	0.21	0.19	0.43**	0.34**
Psychosocial health	0.36**	0.38**	0.67**	0.59***
Emotional functioning	0.29*	0.34**	0.65***	0.55***
Social functioning	0.31*	0.23	0.47***	0.40**
School functioning	0.26*	0.32*	0.47***	0.45***
Parent proxy-report				
Total score	0.49***	0.52***	0.64***	0.65***
Physical health	0.48***	0.31*	0.54***	0.47***
Psychosocial health	0.44***	0.54***	0.61***	0.66***
Emotional functioning	0.37**	0.45***	0.74***	0.67***
Social functioning	0.34**	0.41**	0.39**	0.47***
School functioning	0.31*	0.40**	0.32*	0.41**

CY-BOCS Children's Yale-Brown Obsessive-Compulsive Scale, *CBCL* Child Behavior Checklist

* $P < .005$, ** $P < 0.01$, *** $P < 0.001$

severity as predictors of QoL using four separate hierarchical linear regressions. The PedsQL or PedsQL Parent-Proxy total scores were the criterion variables. The CY-BOCS Total Score and CBCL internalizing/externalizing symptoms were entered together in step one, and the interaction of the CY-BOCS Total Score and respective symptom index was entered in step two. In order to control for the number of analyses conducted, a significance value of 0.0125 was used.

Child PedsQL scores

In the analysis to determine whether internalizing symptoms interacted with OCD severity, step one analyses revealed that internalizing symptoms significantly predicted child-rated QoL ($\beta = -0.60$, $P < 0.001$), but OCD severity did not ($\beta = -0.11$, $P = 0.349$), accounting for 40.1% of the variance in QoL scores [$F(2, 55) = 20.06$, $P < 0.001$]. There was no significant increase in predictive ability when the interaction of OCD severity by internalizing symptoms ($\beta = 0.16$, $P = 0.799$) was added [$F(3, 54) = 13.12$, $P < 0.001$]. In the analysis to determine whether externalizing symptoms interacted with OCD severity, neither symptom severity nor parent-rated externalizing behaviors significantly predicted child-rated QoL independently ($\beta = -0.22$, $P = 0.109$; $\beta = -0.24$, $P = 0.089$, respectively), but together they obtained an adjusted R^2 of 0.132 ($P = 0.008$). There was no significant increase in prediction for the effect for the interaction of OCD severity by externalizing symptoms [$F(3, 52) = 3.99$, $P = 0.0128$].

Parent PedsQL scores

In the analysis to determine whether internalizing symptoms interacted with OCD severity, both parent-rated internalizing symptoms and OCD severity significantly predicted parent-rated QoL ($\beta = -0.50$, $P < 0.001$; $\beta = -0.29$, $P = 0.01$), accounting for 43.1% of the variance in parent PedsQL scores [$F(2, 57) = 23.31$, $P < 0.001$]. There was no significant effect for the interaction of OCD severity by internalizing symptoms ($\beta = 0.93$, $P = 0.112$), leaving the total model an adjusted $R^2 = 0.45$ [$F(3, 56) = 16.84$, $P < 0.001$]. In the analysis to determine whether externalizing symptoms interacted with OCD severity, parent-rated externalizing symptoms significantly predicted parent-rated QoL ($\beta = -0.42$, $P < 0.001$), but clinician-rated OCD severity did not ($\beta = -0.29$, $P = 0.019$). Finally, there was not a significant contribution for the interaction of parent-rated externalizing scores by OCD severity for parent-rated QoL ($\beta = -0.45$, $P = 0.500$).

Discussion

Given the pervasive nature of the disorder, it is not uncommon for children and adolescents with OCD to suffer not only from the core symptoms related to OCD, but also from additional difficulties in important areas of functioning [20]. Overall, results suggest a significant and all-encompassing negative effect of OCD symptoms on QoL in youth, results consistent with previous studies suggesting that the presence of psychopathology is associated with poorer QoL [4, 5, 27]. This highlights the need to focus on QoL in both the assessment and treatment of youth with OCD.

QoL among female OCD patients was poorer than among males, a finding consistent with research indicating that child psychopathology evidences a larger impact on ratings of QoL for girls than for boys [4]. This finding may be indicative of higher rates of internalizing disorders in girls [15], which, as our data suggest, are strongly predictive of QoL. The strong, positive correlations between child- and parent-report across age groups suggest that youth and their parents largely agree about the extent to which QoL is affected by the presence of OCD and comorbid disorders. However, correlations were not perfect, such that child-report and parent-report subscale and total scores shared between 18 (child social functioning) and 58 (adolescent school functioning) percent of variance. Parents generally rated QoL as lower than the youth. One explanation for this is that youths may minimize the impact on QoL of their condition. These results highlight the importance of gathering data from multiple informants to ensure comprehensive understanding of areas in which the youth is negatively affected by his or her illnesses.

The finding that QoL was moderately associated with OCD symptom severity is consistent with previous research showing the relationship between OCD symptom severity and OCD-related functional impairment [20, 35]. However, correlations were small to moderate, suggesting that OCD symptom severity and QoL are two related but distinct constructs. This finding has significant implications for assessment, as assessment should include an evaluation of QoL and/or functional impairment (e.g., Child Obsessive-Compulsive Impact Scale) [20] to facilitate a more accurate representation of OCD-specific impairment and distress experienced by the child. Furthermore, QoL assessment may provide therapists with a greater understanding of the areas in which their particular patient suffers, and might cue therapists to address these areas in initial treatment sessions to foster increased motivation for treatment participation and homework compliance. For example, for a child who has become home-bound due to OCD symptoms, a therapist may highlight that participation in therapy may facilitate school re-entry and increased socialization opportunities. The broad range of scores on QoL measures in our sample suggests the need to carefully attend to the particular subscales and items on which the child scored high in order to identify the specific areas of difficulties that the child is facing. For example, while one child's OCD symptoms may be having a particularly negative effect on school functioning, another's OCD symptoms may lead to difficulties with peer interactions.

The results of regression analyses indicate that knowing the amount of comorbid internalizing or externalizing symptoms can make significant contributions to predictive ability, but OCD severity is of little predictive value. This again reinforces that although symptom severity and QoL are related, they are separate constructs. Being aware of the presence of comorbid disorders can greatly increase our understanding of a child's likely QoL, as results indicated that a large amount of the variance in child- and parent-rated QoL was due to internalizing symptoms. This finding highlights the need for OCD treatment programs to not only address primary OC symptoms, but to also target concerns such as depressive and anxiety symptoms in order to provide comprehensive care and improve overall quality of life. For example, a child with OCD who also presents with social difficulties may benefit from a social skills training intervention in addition to OCD-specific treatment. Given that untreated internalizing symptoms are associated with an increased risk for poor outcomes in the future, such as suicide and substance use, assessing for and treating additional comorbid psychiatric/psychological problems among youth with OCD seems critical for improvements in real-world functioning. Some evidence suggests that family-based cognitive-behavioral interventions for OCD also have success at reducing co-occurring anxiety and depressive symptoms [31], which is likely due to improved functioning from symptom reduction and learning adaptive coping skills that generalize to other problems.

The current findings regarding QoL in pediatric OCD is very similar to results to a previously published study examining child and parent reports of QoL of psychiatric [5] pediatric samples. Both found lowered levels of overall QoL, especially compared to non-clinical [39] pediatric samples. Although the psychiatric sample [5] is European in origin and the current study is American, there were similar diagnostic profiles across the two groups and similar scores on the PedsQL for both parent and child reports. Further studies comparing QoL across diagnostic categories would be very useful, as they could help determine if there are aspects of one's QoL that are differentially impacted by specific disorders, or if there are more similarities than differences.

Despite the significant contributions of the study, certain limitations should be considered. Although rigorous diagnostic procedures were undertaken, a structured diagnostic interview was not used to make diagnoses of OCD and comorbid disorders. A second limitation concerns the cross-sectional nature of the study's design, which limits inferences about the nature and causality of relationships between OCD, comorbid psychological and behavioral problems, and QoL. Prospective longitudinal studies are needed to clarify the directionality of these relationships and to assess the relative influence of specific psychological disorders on QoL. Another limitation pertains to issues of limited generalizability, as the study's sample was primarily Caucasian and the majority of participants came from middle to upper class families. It should also be mentioned that the high rate of comorbidity of this sample, although not uncommon in children with OCD, could have distorted the findings, due to the known impact that these other disorders can have on QoL (e.g., depression) or on the participant's potential ability to appraise his or her own QoL (e.g., Asperger's Disorder). Finally, this study did not examine the effect of treatment on QoL, and therefore there is no indication as to whether cognitive-behavioral therapy or pharmacotherapy positively affects QoL ratings in pediatric samples, as has been found in adult studies [4, 19]. Future studies should include an evaluation of the effect of cognitive-behavioral therapy on QoL to investigate whether this treatment works on multiple levels to enhance functioning in youth with OCD.

Given the relatively poor QoL among pediatric OCD patients across multiple areas of functioning, future research should examine treatment strategies aimed at both enhancing QoL and targeting core OCD symptoms. Studies examining specific predictors of poor QoL in pediatric OCD will be influential in driving the development of these interventions. Among children with psychiatric disorders, the presence of stressful life events, low self-esteem, poor social skills, and poor social support have been found to be predictors of poor QoL [4]. Investigating these predictors as well as others (e.g., age of onset, illness duration) within the field of pediatric OCD will provide useful data for enhancing treatment programs and improving the overall well-being of children suffering from OCD.

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