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Quality of life and burden in caregivers of youth with obsessive-compulsive disorder presenting for intensive treatment

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Abstract

Background—Pediatric obsessive-compulsive disorder (OCD) is associated with deleterious familial effects; caregivers are often enmeshed in the disorder and can experience considerable burden and decreased quality of life (QoL). Consequently, this study examined burden and QoL in caregivers of youth with OCD enrolled in an intensive outpatient or partial hospitalization program.

Method—The relationships between caregiver QoL and burden and the following variables were investigated: OCD symptom severity, functioning (youth functional impairment, general family functioning), family (family accommodation, parental relationship satisfaction, positive aspects of caregiving), and comorbid psychopathology (caregiver anxiety and depressive symptoms, youth internalizing and externalizing behaviors). Seventy-two child and caregiver dyads completed clinician- and self-rated questionnaires.

Results—Components of caregiver QoL correlated with caregiver-rated functional impairment, family accommodation, youth externalizing behaviors, and caregiver psychopathology. Aspects of caregiver burden correlated with child OCD symptom severity, functional impairment related to OCD, as well as caregiver and child comorbid psychopathology. Caregiver depressive symptoms predicted caregiver QoL, and caregiver depressive symptoms and child externalizing symptoms

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both predicted caregiver burden. Caregiver burden did not mediate the relationship between obsessive-compulsive symptom severity and caregiver QoL.

Conclusion—Ultimately, elucidating factors associated with increased caregiver burden and poorer QoL is pertinent for identifying at-risk families and developing targeted interventions.

1. Introduction

Obsessive-compulsive disorder (OCD) is characterized by intrusive thoughts, images, or impulses and/or repetitive rituals [1], affecting 1–2% of youth [2,3]. Studies have documented the adverse impact of pediatric OCD, with functional impairment observed across family, social, and school domains [4–6]. Although OCD-related impairment is experienced broadly across various areas, home life appears to be particularly impacted [6] for both the affected child and his/her family members [7].

Increased obsessive-compulsive symptoms have been associated with negative effects on the family dynamics and environment. Specifically, obsessive-compulsive symptom severity is directly linked with family distress [8–11], and indirectly with family functioning [12–14] and organization [15]. Additionally, Cooper [16] highlighted the unique impact of OCD relative to other mental illnesses, given the direct involvement of family members in the disorder. Because of the age and developmental stages of youth, parental involvement is particularly salient in this population. For instance, many youth with OCD engage their caregivers in their OCD symptomology, such as asking them to directly participate in compulsions, facilitate avoidance of anxiogenic triggers, or modify family schedules. Indeed, family accommodation has been consistently documented in pediatric OCD at high rates [17], with almost half of the families engaging in these behaviors on a daily basis [15]. Unfortunately, family accommodation contributes to higher levels of functional impairment in these youth [18,19].

Given the salience of family involvement in pediatric OCD, it follows that there is a substantial impact on family life and caregiver responsibilities [11,20]. As such, caregiver burden and quality of life (QoL) are particularly important constructs to examine. Caregiver burden is a multifaceted concept, as individuals can experience both objective and subjective types of burden [21]. Quality of life considers the perceptions of the caregiver’s present physical, psychological, social, and living environment [22]. These constructs are often examined jointly, and can also be viewed through a stress process model [23]. These models examine the interplay between the stressors that come with caregiving, the available psychosocial resources, and the well-being of caregivers [24]. Indeed, other factors can mediate the link between caregiver stressors and their well-being, including the amount of social support available, how they view their stressors, and what coping styles they utilize in these situations [25,26]. Considering the variability in the perceptions related to caregiving experiences, there also may be potentially positive aspects of being a caregiver with a family afflicted by chronic illnesses [27]. For instance, certain caregivers may experience an increased sense of self-efficacy or a stronger bond with family members, having gone through these trying situations together [28].

Despite the importance of examining these constructs in caregivers of youth with OCD, the literature is limited. Indeed, existing studies are largely restricted to caregiver burden and QoL in physical illnesses, such as Alzheimer's disease and leukemia [29–34], with little focus on psychiatric illnesses, particularly OCD. Studies in psychiatric conditions have largely focused on schizophrenia [35–40]. There has been limited research on other psychiatric illnesses [41,42]. Specifically, caregivers of youth presenting with myriad diagnoses, such as ADHD [43], Tourette syndrome [44], and neurodevelopmental disorders [45] often experience higher parenting stress relative to caregivers of typically developing children, though stress did not always correlate directly with levels of symptom severity; some comorbid psychopathology (including OCD; [44]) was postulated to be contributing more to the increased parenting stress.

Extant literature on caregiver QoL and burden in OCD has been exclusively limited to adult samples. Within these studies on caregiver QoL, higher patient OCD symptom severity was linked to significantly lower QoL in caregivers across numerous domains of life [46,47], with psychological well-being being particularly negatively impacted by OCD [48,49]. Increased caregiver stress is especially salient within marital relationships and at home [50]. Continued involvement in the symptoms and engaging in accommodating behaviors are predictive of poorer caregiver physical health [48] and decreased QoL [8,51]. Furthermore, longer duration of OCD illness and presence of comorbid depression in the caregiver also predict lower perceived QoL [52].

Family burden for caregivers of adults with OCD is comparable to burden levels experienced by caregivers of patients with schizophrenia [46,53–56], though it is even higher than the burden experienced by caregivers of depressed patients [47] and healthy controls [52,57]. Increased family accommodation is also linked to increased caregiver burden [53,58–60]. Additionally, caregiver psychiatric comorbidity (especially comorbid depression) and the patient's concurrent depressive symptoms both contribute to increased caregiver burden [52,58,60]. A longer course of OCD and poorer patient insight into OCD symptomology are also predictive of heightened caregiver burden [52].

Collectively, caregivers of adults with OCD have demonstrated decreased QoL across various domains and increased caregiver burden, illustrating the impactful role of OCD on the family. Given the prominent role of caregivers in the care of youth, it is important to examine caregiver burden and QoL in pediatric OCD. Previous studies have focused exclusively on the youth, elucidating the negative impact of the disorder on the child's own QoL [61,62]; youth with OCD were observed to have lower QoL relative to healthy controls, particularly when presenting with comorbid psychopathology. These youth also experienced lower QoL when they demonstrated higher levels of OCD symptom severity and family accommodation. However, there have been limited examinations on the unique experiences of the caregiver. The studies that have focused on the parental experiences of caring for a youth with OCD have mostly examined parental coping style [63]. There has only been one study to date that has examined the parental experience and strain of caring for a child with OCD [64]. Concurrent internalizing symptomology in the youth mediated the relationship between parental experiences and parental distress, indicating the compounded difficulties of co-occurring psychopathology. Regarding caregiver strain, objective and subjective internalizing strain (e.g., financial burden, distress due to child's OCD) were positively correlated with OCD symptom severity, though subjective externalizing strain (e.g., embarrassment, anger) did not. Given these deleterious effects of the disorder on the family, it is imperative to conduct further investigations that focus on the parental impact and identify various factors that contribute to lower QoL and higher burden.

There have been no studies that directly examine the QoL of the caregiver of a child with OCD. Consequently, this study investigates caregiver QoL and burden in a pediatric OCD sample receiving intensive treatment for OCD. These youth are of particular interest, as children seeking intensive treatment for OCD are often treatment refractory [65] and typically present with more severe OCD symptoms [66–68]. Our aims and hypotheses are as follows:

1. Examine the associations between OCD symptom severity, OCD-related impairment, and family accommodation with caregiver QoL and burden. Higher OCD symptom severity, related impairment, and family accommodation were expected to be correlated with lower caregiver QoL and higher caregiver burden [48,53,58,59].
2. Investigate the correlation between OCD symptom severity and family variables (i.e., general family functioning and positive aspects of caregiving). More severe OCD symptoms were expected to be associated with a negative impact on the family's overall functioning [20]. It is possible that families can experience unexpected gains in self-efficacy and improved outlook on life while going through this therapeutic process, similar to how caregivers of individuals with cancer have experienced positive aspects of caregiving [28].
3. Examine the relationships between caregiver QoL and burden and comorbid anxiety and depressive symptoms in the caregivers, as well as internalizing and externalizing symptoms in the youth. It is hypothesized that higher levels of comorbid psychopathology in the caregiver, as well as in the youth, will be negatively associated with caregiver QoL and positively associated with caregiver burden [20,58,64].
4. Examine a potential mediational model in which the relationship between OCD symptom severity and caregiver QoL is mediated by caregiver burden. Through the lens of the stress process model, which posits that caregiver well-being is impacted by the caregiver's appraisal of their stressors [25,26,69], the perceived burden may mediate the relationship between OCD symptom severity and caregiver QoL.

2. Methods

2.1. Participants

Participants included 72 youth and caregiver dyads. Youths were 51% male (*n* = 37) with a mean age of 13.24 years (*SD* = 2.70; range = 7–17 years). The majority of participants were Caucasian (*n* = 55), followed by mixed race (*n* = 4), African American (*n* = 2), and Asian (*n* = 2). Caregivers reported a mean age of onset of OCD symptoms of 8.66 years (*SD* = 3.52;

range = 2–15 years), as well as a reported mean age of diagnosis at 10.93 years (*SD* = 3.10; range = 5–16 years). Caregivers were mostly mothers (*n* = 57), with some father (*n* = 7) and other caregiver (*n* = 8) participation. Many caregivers reported an annual income of over $150,000 (*n* = 25), with over half of families reporting incomes higher than $85,000 (*n* = 45). Of note, certain demographic variables were missing on up to 12 participants; please see the Analytic Plan section for the handling of missing data. All participants were recruited from Rogers Behavioral Health–Tampa Bay and Nashville, specializing in the treatment of OCD through intensive outpatient and partial hospitalization programs. Participants were eligible if the youth was (1) between 6 and 17 years of age, (2) had a primary diagnosis of OCD, and (3) had a caregiver available to participate. The diagnosis for OCD was determined through a clinical interview with a board certified child/ adolescent psychiatrist, as well as clinical consensus of meeting DSM-5 criteria for OCD through clinical interactions with the patient and data from self-report questionnaires [1,70,71].

2.2. Procedures

The study underwent the appropriate institutional review boards prior to starting participant enrollment. Informed consent and assent were obtained from the caregiver and youth, respectively, before commencing study procedures. If the family decided to participate in the study, the parent-child dyad underwent a single time point battery of clinician-rated and self-reported questionnaires immediately thereafter. All families were enrolled for the study within the first week of care to ensure that the timeframes of the assessment battery were consistent; participants were instructed to complete the questionnaires at their convenience, as long as they were returned within a week of the initial assessment (with a grace period of up to 10 days). Clinician-administered measures were administered first, followed by self-report measures. No compensation was provided for study participation.

2.3. Measures

2.3.1. Children’s Yale-Brown Obsessive Compulsive Scale (CY-BOCS)—The CY-BOCS is a clinician-administered, semi-structured interview that assesses the presence and severity of obsessive-compulsive symptoms in the child. The first section contains a symptom checklist and the second section contains a 10-item severity scale that garners separate severity scores for obsessions and compulsions, as well as a total symptom severity score. The CY-BOCS total score exhibits high internal consistency, good to excellent inter-rater reliability, satisfactory convergent and divergent validity [72,73], as well as treatment sensitivity [74,75].

To determine inter-rater reliability on the CY-BOCS for the present study, the intraclass correlation coefficient (ICC) was calculated within a two-way random effects model, measuring absolute agreement. The inter-rater reliability (*n* = 5 of cross-ratings) for the Obsession Severity scale was excellent (ICC = 0.99, 95% CI [0.93,1.00]). The reliability for the Compulsion Severity scale was excellent as well (ICC = 0.95, 95% CI [0.40, 0.99]), and the reliability for the Total Severity scale was excellent (ICC = 0.99, 95% CI [0.92, 1.00]).

2.3.2. Family Accommodation Scale for Obsessive-Compulsive Disorder–Interviewer-Rated (FAS-IR)—The FAS-IR is a 12-item clinician administered, semi-structured interview that assesses the presence and frequency of OCD-related accommodating behaviors made by the caregiver for the child in the previous week. The FAS-IR items are provided on a scale from 0 to 4; a total score is calculated by summing all of the items, with higher scores indicating more frequent symptom accommodation. The FAS-IR total score has exhibited good agreement across raters, convergent and divergent validity, and internal consistency [76].

2.3.3. Caregiver Burden Inventory (CBI)—The CBI [77] is a 24-item caregiver self-report questionnaire that assesses caregiver burden. Reflecting the multidimensionality of burden, the items on the CBI form 5 subscales: Time Dependency, Development, Physical Health, Emotional Health, and Social Relationships. Scores from each subscale can be garnered separately, or all of the items can be summed to form a total score, with higher scores indicating more significant burden. The CBI subscale scores have demonstrated good internal consistency, and the total score has similarly exhibited adequate to excellent internal consistency, content validity, and concurrent validity [77–79].

2.3.4. World Health Organization Quality of Life–BREF (WHOQOL-BREF)—The WHOQOL-BREF [22] is a 26-item self-report questionnaire completed by the caregiver that assesses the respondent's quality of life in the previous four weeks. Lower scores indicate poorer quality of life. Total scores can be garnered across four life domains: Physical Health, Psychological, Social Relationships, and Environment. Total scores were transformed, though the respondent's overall perception of their QoL was acquired through one question that was non-transformed. The WHOQOL-BREF demonstrates good internal consistency, test-retest reliability, content validity, discriminant validity, and construct validity [22,80]. Additionally, this measure has been validated extensively in samples of families with OCD [46,47,49,52,53].

2.3.5. Sheehan Disability Scale (SDS)—The SDS is a 3-item self-report measure (completed by the parent and the child separately) that examines the OCD-related functional impairment experienced by the youth with OCD. Domains of interference are assessed across family, social, and school. Responses are provided on a scale from 0 to 10, with 0 meaning "*not at all*" and 10 meaning "*extremely*." Items are summed to form a total impairment score, with higher scores indicating greater impairment due to OCD. The SDS scores have exhibited good validity, internal consistency, and sensitivity to change [81,82].

2.3.6. Family Assessment Device–12-Item Version (FAD-12)—The FAD-12 [83] is a 12-item self-report questionnaire completed by the caregiver, assessing general family functioning. A total score is garnered from summing the items, and higher scores indicate poorer family functioning [84]. The FAD-12 is the "General Functioning" subscale of original 53-item FAD measure, which has been utilized in other studies investigating OCD and its impact on the family [76,85,86]. This truncated version of the FAD measure has high internal consistency, differentiates between clinical and nonclinical populations [83], and demonstrates good validity and reliability [87].

2.3.7. Positive aspects of caregiving—The Positive Aspects of Caregiving measure [28] is a 9-item self-report measure completed by the caregiver, assessing the presence of positive experiences of being a caregiver. Items are rated on a scale from 0 to 5, with higher scores indicating stronger agreement with positive experiences of caregiving. Two subscales can be calculated; items either assess content related to self-affirmation or to their outlook on life. Both subscales yielded high internal consistency and the scale generally demonstrates good face validity [28].

2.3.8. Depression Anxiety Stress Scale–Short Version (DASS21)—

The DASS21 [88] is a 21-item self-report questionnaire completed by the caregiver, assessing the presence and severity of stress, anxiety, and depressive symptoms in the caregiver over the past week. Subscale scores can be calculated for anxiety, stress, and depressive symptoms separately, with higher scores indicating more severe symptoms. The DASS21 has demonstrated adequate to excellent internal consistency, as well as concurrent validity [89].

2.3.9. Child Behavior Checklist (CBCL)—

The CBCL is a 113-item caregiver-report questionnaire that assesses the presence and severity of emotional and/or behavioral problems in youth. For the purposes of this study, the Internalizing and Externalizing subscales of the CBCL were of particular interest. The CBCL scores have demonstrated excellent inter-parent agreement, test-retest reliability [90], and the diagnostic scale scores exhibit good discriminant and convergent validity, along with good reliability [91].

2.4. Analytic plan

Descriptive data were examined for each study variable, including the mean, *SD*, and range (see Tables 1–4). Pearson product-moment correlations were calculated to determine the linear relationships between caregiver burden/QoL and variables of interest. Hierarchical multiple regressions were conducted to determine unique predictors of caregiver QoL and burden (beyond the contributions of sociodemographic variables and obsessive-compulsive symptom severity). To examine the mediational model, the PROCESS macro in SPSS was employed as described by Hayes [92]; this method allows for testing of the specific mediational effect with higher power due to bootstrapped resampling [93]. Bootstrap resamples were set to 5000 and mediators were interpreted as statistically significant if their 95% CI did not include 0.

Regarding missing data, the most common reason was due to caregivers and/or youths having difficulty completing their respective self-report questionnaires ($n = 12$; most frequently due to perceived burden). For other cases, single assessment measures were missing due to respondent errors (e.g., filling out measures incorrectly), $n = 5$. For the remainder of the missing data, item-level data were missing sporadically. For measures that had <10% of their data missing and/or satisfied the imputation criteria reported specifically for that measure, mean imputation was utilized; if these criteria were not satisfied, the participant was excluded from that measure's analyses. Please see the notes under Tables 1–4 for the exact number of participants that completed each respective measure.

3. Results

3.1. Caregiver QoL and burden and OCD-related variables

Only parent-rated child functional impairment and family accommodation were related to various aspects of caregiver QoL; higher impairment and accommodation were related to poorer QoL. Child obsessive-compulsive symptom severity, functional impairment, and family accommodation were positively correlated with different components of caregiver burden. See Tables 1 and 2 to view the specific Pearson correlations between caregiver QoL/ burden and OCD-related variables.

3.2. Child OCD symptoms and family variables

Child obsessive-compulsive symptom severity was not statistically significantly correlated with general family functioning or positive aspects of caregiving (Table 3).

3.3. Caregiver QoL, caregiver burden, and comorbid psychopathology

Higher caregiver anxiety and depressive symptoms were related to poorer caregiver QoL and burden across various domains. Greater youth internalizing and externalizing symptoms were linked to higher caregiver burden in various domains, but only youth externalizing symptoms negatively correlated with overall caregiver QoL. The full correlational matrix can be viewed on Tables 1 and 2. Of note, independent sample *t*-tests did not reveal any gender differences on youth internalizing symptoms, $t(62) = -0.11$, $p = 0.91$, nor externalizing symptoms, $t(62) = 0.38$, $p = 0.70$.

3.4. Predicting caregiver QoL and burden with comorbid psychopathology

Results from the respective hierarchical regressions are in Table 5. Youth (internalizing and externalizing symptoms) and caregiver (anxiety and depressive symptoms) psychopathology were examined as potential predictors of caregiver QoL, after controlling for sociodemographic variables (i.e., child age, child sex, child ethnicity, child age at first OCD symptom emergence, annual household income, and care-giver age) and obsessive-compulsive symptom severity. In the first step of the hierarchical multiple regression, sociodemographic variables were not significant predictors of caregiver QoL, $F(1, 49) = 0.82$, $p = 0.56$. In the second step of the regression, obsessive-compulsive symptom severity was not a significant predictor of caregiver QoL either, $F(1, 48) = 0.41$, $p = 0.53$. When considering youth and caregiver psychopathology in the third step of the regression, only caregiver depressive symptoms emerged as a statistically significant predictor of caregiver QoL, $F(4, 44) = 4.86$, $p = 0.002$, with this model accounting for about 38% of the variance in caregiver QoL. This suggests that higher levels of caregiver depressive symptoms are associated with poorer overall caregiver QoL.

After controlling for the aforementioned sociodemographic variables and obsessive-compulsive symptom severity, youth (internalizing and externalizing symptoms) and caregiver (anxiety and depressive symptoms) psychopathology were examined as potential predictors of caregiver burden. In the first step, sociodemographic variables were not significant predictors of caregiver burden, $F(1, 48) = 1.12$, $p = 0.36$. In the next step, obsessive-compulsive symptom severity again did not emerge as a statistically significant predictor of caregiver burden, $F(1, 47) = 3.08$, $p = 0.09$. In the third step of the regression, this model accounted for 57% of the variance in caregiver burden, $F(4, 43) = 9.80$, $p < 0.001$. Specifically, youth externalizing behaviors and caregiver depressive symptoms emerged as significant predictors, indicating that these comorbid symptoms are linked with higher levels of caregiver burden.

3.5. Mediational model

Caregiver burden was tested as a potential mediator for the relationship between child OCD symptom severity and caregiver QoL. Child OCD symptom severity did not predict caregiver burden, $\beta = 0.43$, $t(60) = 1.19$, $p = 0.24$. Care-giver burden was a statistically significant predictor of caregiver QoL, $\beta = -0.04$, $t(60) = -7.27$, $p < 0.001$. The total effect [93] of OCD symptom severity on caregiver QoL was not significant, $\beta = 0.03$, $t(60) = 0.14$, $p = 0.89$. Lastly, the direct effect [93] of child OCD symptom severity on caregiver QoL was not significant, $\beta = 0.02$, $t(60) = 1.30$, $p = 0.20$. Ultimately, caregiver burden did mediate the relationship between child OCD symptom severity and caregiver QoL ($\beta = -0.02$, 95% CI [−0.05, 0.01]).

4. Discussion

This study examined caregiver burden and QoL in children with OCD presenting for intensive treatment. Surprisingly, obsessive-compulsive symptom severity did not correlate with any caregiver QoL variables. It is possible that the nature of the sample may have impacted findings; for instance, these families could have habituated to a new baseline level of functioning and no longer perceive the differences in caregiver functioning. Alternatively, it could be that there are other variables that are mediating the relationship, suggesting that there may be sequelae to OCD (e.g., decreased school functioning, poor independence with self-care) that are indirectly impacting caregiver QoL. More severe obsessive-compulsive symptoms were linked with higher caregiver time dependency, reflecting the burdensome nature of needing to attend to emergent symptomology. For instance, youth that have extensive cleaning rituals may prevent the caregiver from leaving the house on time or cause the caregivers to engage in other time-consuming rituals with the child. Consequently, caregivers' development and social relationships were negatively impacted as well when youth were experiencing higher OCD-related impairment and heightened family accommodation, reflecting the all-encompassing nature of the disorder. Indeed, family accommodation was particularly tied to caregiver's psychological well-being; caregivers may struggle with how to handle requests for accommodation, wrestling with distress/ consequences of not accommodating and knowing that accommodating reinforces the symptomology [94]. With these data, it will be important to provide psychoeducation about how family accommodation not only affects the child but also the accommodator, incorporating these behaviors into the treatment plan as indicated (e.g., decreasing time spent on washing the patient's belongings).

Surprisingly, obsessive-compulsive symptom severity was not correlated with any other family variables, including general family functioning and positive aspects of caregiving. It is possible that these nonsignificant effects are due to the type of measure used; perhaps only specific aspects of these constructs are related to symptom severity. For instance, the FAD is a measure of general family functioning; it could be that a specific component of the family functioning (e.g., interaction style) is impacted by obsessive-compulsive symptoms [95]. Additionally, given that youths were presenting for intensive treatment, the sample may have been limited (and skewed) towards the more severe end of the distribution, precluding the ability to observe a correlation due to the limited variance. Ultimately, it would be beneficial to examine family variables with other constructs and/or examine specific aspects of the variables (e.g., how the family functions as a whole when doing day-to-day tasks) to best understand the nuances of these bidirectional relationships [96].

When considering comorbid psychopathology, higher caregiver anxiety and depressive symptoms were linked with poorer QoL and higher burden. Caregivers with heightened anxiety appear to demonstrate poorer QoL in the physical, psychological, and environment domains, as well as total burden and burden in social relationships. Given these data, it could be beneficial to encourage caregivers to maintain their social connections and a network of support to prophylactically buffer the impact experienced by caregiving [25,97]. Additionally, symptoms of anxiety could be targeted to ameliorate avoidant and other maladaptive management strategies to help them develop more adaptive coping techniques. Caregiver depressive symptoms were negatively linked with all aspects of caregiver QoL and almost all components of burden, highlighting the robust and deleterious effects of experiencing these symptoms [52]. Considering the profound impact of caregiver depressive symptoms, care should be taken to screen for these symptoms and target them accordingly with evidence-based interventions (e.g., cognitive-behavioral therapy, behavioral activation) that address the related issues on multiple levels (e.g., individual, family/environment). Collectively, it is unclear if the caregiver's psychopathology contributed to poorer QoL or if the poorer QoL contributes to and/or exacerbates the caregiver's symptoms, likely reflecting the bidirectional nature of these relationships. Further prospective studies should clarify these dynamics, and interventions should work to target the life domains being impacted as well as the psychological symptoms that may be impacting the caregiver's well-being.

Contrastingly, when examining the impact of child comorbid psychopathology, higher child internalizing symptoms were linked with higher levels of total caregiver burden and time dependency, but were not related to any caregiver QoL variables. As such, caregivers of youth that present with comorbid anxiety/depressive symptoms may be spending more time assuaging fears and providing extra emotional support [58], mostly requiring the caregiver to spend more time with the child in these efforts. In these cases, psychoeducation and skill building should be provided to the family to help promote the child's self-efficacy and encourage supportive coaching in coping with these symptoms. On the other hand, higher levels of child externalizing behaviors were linked with poorer general QoL for the caregiver, as well as higher total caregiver burden and time dependency, development, and emotional health burdens. Given that externalizing symptoms predicted higher caregiver burden, it appears that caregivers of these youth present with a higher risk of experiencing increased burden. Specifically, these symptoms may require more caregiver attention, negatively affecting their attitudes about their own development and fostering a more negative relationship between the child and the parent. To optimize caregiver well-being and facilitate the most effective care for the youth, interventions focusing on behavior-based parent training should be promoted to encourage effective management of these behaviors [98], especially given the known interplay between rage outbursts/behavioral difficulties and increased OCD-related functional impairment [71].

Within the context of the stress process model, the relationship between child obsessive-compulsive symptom severity and caregiver QoL was not anticipated to be linear; other factors, such as caregiver appraisals of burden, coping style, and available resources are hypothesized to mediate this relationship [25,32,69]. In this study, caregiver burden did not mediate the relationship between obsessive-compulsive symptom severity and caregiver well-being. It is possible that only certain aspects of burden and/or QoL may be related to one another, such as primary versus secondary burdens or objective versus subjective burdens. Alternatively, perhaps there are multiple mediators (e.g., coping style, comorbid psychopathology) that are acting upon this relationship; future studies should seek to clarify these dynamics in a more multifaceted manner.

There are several study limitations. First, the study was cross-sectional in nature, so the directionality of the effects and causality of the variables cannot be ascertained. It is likely that the relationships are bidirectional in nature (e.g., perceived caregiver burden influencing caregiver QoL, and caregiver QoL influencing the amount of burden being experienced). Second, most participants were upper-middle class Caucasian families, potentially limiting the generaliz-ability of the findings. Third, caregivers participating in this study were primarily mothers; future studies are encouraged to examine these findings in other caregivers (e.g., fathers, grandparents) and family members (e.g., siblings) and determine potential differences in familial experiences [99]. Fourth, since there are a number of different measures available for measuring caregiver QoL and burden, it is suggested that future studies examine these constructs with alternative measures to tap into the various nuances of these variables. For instance, a measure focusing more on QoL related to psychological well-being (versus physical) may be helpful to determine the cognitive impact of caregiving for youths with OCD, particularly because mental illness incurs higher caregiver emotional burden [100]. Fifth, it would be important for future studies to place these examinations within a developmental perspective. Specifically, studies examining potential phenomenological and clinical differences in caregiver experiences across age groups would be helpful, given the different expectations and varying levels of caregiver involvement when considering a young child versus an older adolescent. Sixth, there are certain characteristics of the caregivers that are unknown in this sample, necessitating future considerations. For instance, certain variables that could influence the caregiver experiences (e.g., other caregiving roles beyond caring for the child with OCD, total number of children/family members) would be important to examine to determine cumulative effects that may impact caregiver QoL/burden. Seventh, no data were collected on psychotropic medications in use by the patient or by the caregiver, which could have potentially impacted caregiver QoL. Future studies should seek to gather a broader treatment history to determine other variables that may contribute to caregiver experiences.

Ultimately, considering the lack of research on the QoL and burden of caregivers of youth with OCD, this study functions as the first joint investigation of these constructs in a pediatric sample. Parents and other caregivers are integral and pertinent to the well-being of their children, but their own well-being and health are often neglected, necessitating quantitative investigations of the deleterious impact of OCD on the caregivers. Results highlighted the robust and detrimental impact of caregivers presenting with heightened depressive symptoms and child externalizing symptoms. Consequently, families presenting with these symptoms are at heightened risk for experiencing negative impacts in caregiver well-being across various domains, suggesting the need for targeted identification and interventions for managing these symptomology. Ultimately, by identifying certain factors associated with reduced caregiver QoL and increased burden, it is hoped that these data will prove beneficial in identifying at-risk families and inform more targeted interventions.

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Table 1

Means, standard deviations, and ranges for study variables.

	CY-BOCS Total	SDS-P	SDS-C	FAS Total	DASS Anx	DASS Dep	CBCL Int	CBCL Ext
Mean	28.01	21.79	18.19	12.41	5.84	10.45	26.50	13.13
SD	5.86	6.58	7.57	23.60	6.09	9.75	12.00	9.58
Range	9–38	0–30	0–30	0–48	0–28	0–42	0–58	0–46

CY-BOCS = Children’s Yale-Brown Obsessive Compulsive Scale total score (*n* = 71); SDS-P/C = Sheehan Disability Scale – Parent/Child Report total score (*n* = 62/64); FAS = Family Accommodation Scale for Obsessive-Compulsive Disorder total score (*n* = 70); DASS = Depression Anxiety Stress Scale – Short Version (Anx = Anxiety/Dep = Depression; subscales *n* = 62–64); CBCL = Child Behavior Checklist (Int = Internalizing/Ext = Externalizing subscales; *n* = 64).

Table 2

Means, standard deviations, ranges, and correlations between caregiver QoL and study variables.

	Caregiver QoL (WHOQOL-BREF)				
	General	**Physical**	**Psychological**	**Social**	**Environment**
CY-BOCS	−0.03	−0.05	0.09	0.05	0.08
SDS-P	-0.27^{*}	−0.19	−0.13	0.00	−0.10
SDS-C	−0.09	0.01	0.10	0.13	0.08
FAS	−0.20	−0.13	-0.26^{*}	−0.11	−0.01
DASS anxiety	−0.11	-0.45^{***}	-0.45^{***}	−0.14	-0.29^{*}
DASS Depression	-0.43^{***}	-0.58^{***}	-0.84^{***}	-0.50^{***}	-0.55^{***}
CBCL – Int	−0.15	−0.20	−0.18	−0.10	−0.22
CBCL – Ext	-0.25^{*}	−0.14	−0.16	−0.07	−0.15
Mean	3.09	65.57	56.77	52.65	67.82
SD	1.00	16.54	19.61	20.68	17.09
Range	1–5	25–96	0–92	0–100	16–97

WHOQOL-BREF = World Health Organization Quality of Life – BREF (subscales $n = 63$–64); CY-BOCS = Children’s Yale-Brown Obsessive Compulsive Scale total score ($n = 71$); SDS-P/C = Sheehan Disability Scale – Parent/Child Report total score ($n = 62/64$); FAS = Family Accommodation Scale for Obsessive-Compulsive Disorder total score ($n = 70$); DASS = Depression Anxiety Stress Scale – Short Version (subscales $n = 62$–64); CBCL = Child Behavior Checklist (Int = Internalizing/Ext = Externalizing subscales; $n = 64$).

$^{*}p < 0.05$.

$^{***}p < 0.001$.

Table 3

Means, standard deviations, ranges, and correlations between caregiver burden and study variables.

	Caregiver burden (CBI)					
	Total	**Time dependency**	**Development**	**Physical health**	**Social relationships**	**Emotional health**
CY-BOCS	0.15	0.43***	0.10	−0.12	0.21	0.07
SDS-P	0.46***	0.53***	0.40**	0.22	0.26*	0.29*
SDS-C	0.05	0.33*	0.12	−0.09	−0.07	0.00
FAS	0.49***	0.67***	0.34**	0.18	0.34**	0.22
DASS anxiety	0.35**	0.23	0.14	0.23	0.43***	0.08
DASS Depression	0.49***	0.22	0.34**	0.50***	0.55***	0.28*
CBCL – Int	0.25*	0.33**	0.15	−0.00	0.20	0.23
CBCL – Ext	0.42***	0.32***	0.25*	0.14	0.18	0.54***
Mean	42.90	9.72	12.25	8.58	6.76	4.95
SD	16.16	4.79	5.10	3.60	4.62	4.39
Range	10–96	0–20	2–20	2–16	0–20	0–20

CBI = Caregiver Burden Inventory (subscales *n* = 62–64); CY-BOCS = Children’s Yale-Brown Obsessive Compulsive Scale total score (*n* = 71); SDS-P = Sheehan Disability Scale – Parent/Child Report total score (*n* = 62/64); FAS = Family Accommodation Scale for Obsessive-Compulsive Disorder total score (*n* = 70); DASS = Depression Anxiety Stress Scale – Short Version (subscales *n* = 62–64); CBCL = Child Behavior Checklist (Int = Internalizing/Ext = Externalizing subscales; *n* = 64).

$^{*}p < 0.05$.

$^{**}p < 0.01$.

$^{***}p < 0.001$.

Table 4

Means, standard deviations, ranges, and correlations between OCD symptom severity and family variables.

	FAD	PAoC	PAoC	PAoC
		Self-affirmation	Outlook on life	Total
CY-BOCS	0.06	−0.09	0.05	−0.05
Mean	25.89	17.03	8.64	25.67
SD	8.62	5.72	3.27	7.68
Range	12–48	6–28	3–15	9–41

CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale total score (*n* = 71); FAD-12 = Family Assessment Device – 12 Item Version total score (*n* = 63); PAoC = Positive Aspects of Caregiving (*n* = 64).

Table 5

Hierarchical multiple regression analyses for predicting caregiver QoL and burden beyond OCD symptom severity.

Predictor	***B***	***SE*(*B*) [95% CI]**	***β***	R^2	ΔR^2	***F* for** ΔR^2
Predicting Caregiver QoL						
Step 1						
Child age	−0.05	0.06 [−0.17, 0.07]	−0.15			
Child sex	−0.09	0.28 [−0.65, 0.47]	−0.05			
Child ethnicity	−0.90	1.04 [−2.98, 1.18]	−0.12			
Age of OCD symptom emergence	0.02	0.04 [−0.07, 0.11]	0.07			
Household income	0.12	0.07 [−0.02, 0.25]	0.24			
Caregiver age	0.02	0.03 [−0.04, 0.08]	0.11	0.09		
Step 2						
CY-BOCS total	−0.02	0.03 [−0.07, 0.03]	−0.09	0.10	0.01	0.41
Step 3						
CBCL internalizing	0.00	0.02 [−0.03, 0.03]	0.03			
CBCL externalizing	−0.03	0.02 [−0.07, 0.00]	−0.30			
DASS anxiety	0.06	0.03 [−0.01, 0.12]	0.37			
DASS depression	−0.06	0.02 [−0.10, −0.03]	−0.61**	0.38	0.28	4.86**
Predicting Caregiver Burden						
Step 1						
Child age	−0.96	0.98 [−2.93, 1.01]	−0.16			
Child sex	3.49	4.61 [−5.79, 12.76]	0.11			
Child ethnicity	25.20	16.95 [−8.89, 59.28]	0.21			
Age of OCD symptom emergence	−0.04	0.75 [−1.53, 1.46]	−0.01			
Household income	−0.62	1.09 [−2.81, 1.56]	−0.08			
Caregiver age	−0.15	0.48 [−1.11, 0.81]	−0.05	0.12		
Step 2						
CY-BOCS Total	0.70	0.40 [−0.10, 1.49]	0.24	0.18	0.05	3.08
Step 3						
CBCL internalizing	0.00	0.22 [−0.44, 0.44]	0.00			
CBCL externalizing	0.74	0.24 [0.25, 1.22]	0.42**			

Predictor	***B***	***SE*(*B*) [95% CI]**	**β**	**R^2**	**ΔR^2**	***F* for ΔR^2**
DASS anxiety	−0.35	0.47 [−1.29, 0.60]	−0.13			
DASS depression	0.88	0.27 [0.33, 1.42]	0.53 **	0.57	0.39	9.80 ***

CY-BOCS = Children’s Yale-Brown Obsessive Compulsive Scale; DASS = Depression Anxiety Stress Scale – Short Version; CBCL = Child Behavior Checklist.

** $p < 0.01$.

*** $p < 0.001$.