

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 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.

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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.

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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

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