Graduate Theses and Dissertations   Graduate School

May 2017

Quality of Life and Burden in Caregivers of Youth with Severe Obsessive-Compulsive Disorder

Monica S. Wu
University of South Florida, monicawu@mail.usf.edu

Follow this and additional works at: http://scholarcommons.usf.edu/etd

Part of the Clinical Psychology Commons

Quality of Life and Burden in Caregivers of Youth with Severe Obsessive-Compulsive Disorder

by

Monica S. Wu

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
with a concentration in Clinical Psychology
Department of Psychology
College of Arts and Sciences
University of South Florida

Co-Major Professor: Eric Storch, Ph.D.
Co-Major Professor: Vicky Phares, Ph.D.
Brent Small, Ph.D.
Joseph Vandello, Ph.D.
J. Kevin Thompson, Ph.D.
Adam Lewin, Ph.D.

Date of Approval:
May 5, 2017

Keywords: Child, Caregiver Experiences, Depression, Externalizing

TABLE OF CONTENTS

LIST OF TABLES

ABSTRACT

Pediatric obsessive-compulsive disorder (OCD) is a heterogeneous disorder associated with functional impairment and deleterious effects at the family level. Caregivers are often enmeshed in the disorder, coping with the child's OCD-related distress and engaging in accommodating behaviors. Given the developmental level of these youth and the impactful nature of OCD, caregivers may experience considerable burden and decreased quality of life (QoL). However, extant literature on these constructs is largely limited to caregivers of patients with chronic illnesses, and the few existing studies examining OCD samples are limited to adult patients. As such, this study sought to examine burden and QoL in caregivers of youth enrolled in an intensive outpatient or partial hospitalization program for their severe OCD. Specifically, 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 participated in the study and completed a battery of clinician- and self-rated questionnaires. Different components of caregiver QoL correlated with caregiver-rated functional impairment, family accommodation, youth externalizing behaviors, and caregiver psychopathology. Various aspects of caregiver burden correlated with 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.   Ultimately, elucidating

factors associated with increased caregiver burden and poorer QoL are pertinent for the

identification of at-risk families and development of targeted interventions.

INTRODUCTION

Obsessive-compulsive disorder (OCD) is a heterogeneous psychiatric disorder characterized by obsessions and/or compulsions (American Psychiatric Association, 2013), affecting around 1-2% of youth (Geller, 2006; Zohar, 1999). Obsessions can manifest through intrusive images, thoughts, feelings, or impulses, while compulsions are typically characterized by repetitive rituals, behaviors, or mental acts. Studies have documented the deleterious impact of pediatric OCD, with functional impairment observed across family, social, and school domains of life (Piacentini, Peris, Bergman, Chang, & Jaffer, 2007; Storch, Rudy, Wu, Lewin, & Murphy, 2014; Valderhaug & Ivarsson, 2005). For instance, youth with OCD may display increased difficulty with concentrating on schoolwork due to intrusive thoughts, while other youth may be unable to complete simple tasks at home due to time spent on compulsions. Although OCD-related impairment is experienced broadly across various areas, home life appears to be particularly impacted (Valderhaug & Ivarsson, 2005). The negative impact of pediatric OCD is not limited to the youth, as it is often observed beyond the level of the patient with OCD (Lebowitz, Panza, Su, & Bloch, 2012).

Increased obsessive-compulsive symptoms have been associated with negative effects on the family dynamics and environment. Specifically, higher obsessive-compulsive symptom severity is linked with higher levels of family distress (Albert et al., 2010; Amir, Freshman, & Foa, 2000; Ferrao et al., 2006; Futh, Simonds, & Micali, 2012), as well as lower levels of family functioning (Calvocoressi et al., 1995; Maina, Saracco, & Albert, 2006; Steketee & Van Noppen, 2003) and organization (Peris et al., 2008). Additionally, Cooper (1996) highlighted the unique

impact of OCD (as compared to other mental illnesses), given the direct involvement of family members in the disorder. With the age and developmental stages of these youth, parental involvement is particularly salient in this population.

Many youth with OCD engage their caregivers in their OCD symptomology, such as asking them to directly participate in their compulsions, facilitate avoidance of anxiogenic triggers, or modify family schedules. Indeed, family accommodation has been consistently documented in pediatric OCD at high rates (Storch et al., 2007), with almost half of the families engaging in these behaviors on a daily basis (Peris et al., 2008). Unfortunately, family accommodation contributes to higher levels of functional impairment in these youth (Caporino et al., 2012; Storch, Larson, et al., 2010). Furthermore, recent literature has elucidated the presence of rage and disruptive behaviors within pediatric OCD (Storch et al., 2012), as youth may become increasingly aggressive, distressed, and angry when their symptoms are not accommodated (Peris et al., 2008; Wu, Lewin, Murphy, Geffken, & Storch, 2014). Consequently, caregivers can also feel distressed and coerced into engaging in these maladaptive behaviors in an effort to quell the youth's negative valence state (Lebowitz, Vitulano, & Omer, 2011). While these behaviors are often carried out with good intentions, they operate contrary to the principles of exposure and response prevention, the first-line treatment for pediatric OCD (American Academy of Child and Adolescent Psychiatry, 2012). Specifically, symptom accommodation precludes the youth from facing their feared situations, and thus prevents them from learning more adaptive appraisals and behaviors. Ultimately, symptom accommodation serves to not only maintain the OCD symptomology, but also ensures the continued enmeshment of family members in the disorder.

Given the salience of family involvement in pediatric OCD, it follows that there is a substantial impact on family life and caregiver responsibilities (Black, Gaffney, Schlosser, & Gabel, 1998; Futh et al., 2012). As such, caregiver burden and quality of life (QoL) are particularly important constructs to examine, given the all-encompassing nature of the disorder. Caregiver burden is a multifaceted concept, as individuals can experience both objective and subjective types of burden (Fadden, Bebbington, & Kuipers, 1987; Hoenig & Hamilton, 1966). Within objective burden, caregivers may be affected by factors such as financial burden incurred from patient care or disruption in daily schedules. Alternatively, subjective burden is more consistent with the caregiver's perception of the level of burden they believe they are carrying. Quality of life similarly considers the perceptions of the caregiver's present physical, psychological, social, and living environment (The WHOQOL Group, 1998). These constructs are often examined jointly, given that they both consider the objective and subjective impact of disorders on the caregiver (de Oliveira et al., 2014; Foldemo, Gullberg, Ek, & Bogren, 2005; Grad & Sainsbury, 1963; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Morimoto, Schreiner, & Asano, 2003; Sales, 2003).

Despite the importance of examining these constructs in caregivers of youth with OCD, the extant literature is significantly limited. Indeed, existing studies are largely restricted to caregiver burden and QoL in physical illnesses, such as Alzheimer's disease and leukemia, demonstrating the harmful impact of these conditions on QoL and burden for these caregivers (Gothwal, Bharani, & Mandal, 2015; Jastrowski Mano, Khan, Ladwig, & Weisman, 2011; Krattenmacher et al., 2014; Schulz & Beach, 1999; Stromberg & Luttik, 2015; Yamazaki, Sokejima, Mizoue, Eboshida, & Fukuhara, 2005). There unfortunately has not been equal attention placed on caregivers of patients with mental health difficulties, despite the significantly

higher emotional burden and impairment in health-related QoL (Settineri, Rizzo, Liotta, & Mento, 2014; Spitzer et al., 1995) experienced by these caregivers (when compared to caregivers of individuals with physical illnesses). Additionally, the existing research that investigates caregiver burden and QoL in mental disorders has largely focused on more severe psychiatric illnesses, namely schizophrenia, documenting the expansive, negative effects of these disorders on caregivers (Awad & Voruganti, 2008; Caqueo-Urizar, Gutierrez-Maldonado, & Miranda-Castillo, 2009; Foldemo et al., 2005; Gater et al., 2014; Hsiao & Tsai, 2014; Saunders, 2003). Consequently, there has unfortunately been a paucity of research conducted on other specific psychiatric illnesses (Armstrong, Lycett, Hiscock, Care, & Sciberras, 2014; Lee, Harrington, Louie, & Newschaffer, 2008), including OCD.

Drawing from the literature on caregiver experiences in primarily physical, medical illnesses, the role in which stress impacts the experience of caregiving has been examined through a stress process model (Pearlin, Mullan, Semple, & Skaff, 1990). These models examine the interplay between the stressors that come with caregiving, the available psychosocial resources, and the well-being of caregivers (Goode, Haley, Roth, & Ford, 1998). The primary stressors are those that are experienced from a direct impact of caregiving (e.g., having to address self-care difficulties, emergent behavioral impacts), with secondary stressors arising from subsequent difficulties experienced due to caregiving (e.g., negative impact on self-concept, decreased involvement in other activities). However, 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 (Haley, Levine, Brown, & Bartolucci, 1987; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Indeed, the impact of caregiver stressors is not necessarily linear, highlighting the importance of

considering mediating factors that incorporate the interaction of the individual and their respective environment (Haley et al., 1987). In a related body of literature, there are found to be potentially positive aspects of being a caregiver with a family afflicted by physical illnesses, highlighting the variability in the perceptions related to caregiving experiences (C. A. Cohen, Colantonio, & Vernich, 2002). 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 (Tarlow et al., 2004).

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, such as physiological health and social functioning (Grover & Dutt, 2011; Vikas, Avasthi, & Sharan, 2011), with psychological well-being being particularly negatively impacted by OCD (Albert, Salvi, Saracco, Bogetto, & Maina, 2007; Stengler-Wenzke, Kroll, Matschinger, & Angermeyer, 2006). Increased caregiver stress is especially salient within marital relationships and at home (Laidlaw, Falloon, Barnfather, & Coverdale, 1999), emphasizing the expansive impact of the disorder. Continued involvement in the symptoms and engaging in accommodating behaviors are predictive of poorer caregiver physical health (Albert et al., 2007) and decreased QoL (Albert et al., 2010; Cherian, Pandian, Bada Math, Kandavel, & Janardhan Reddy, 2014), highlighting the necessity to eliminate family accommodation in patients with OCD. Certain caregiver demographic characteristics, such as older age and female sex, are associated with poorer QoL as well (Albert et al., 2007; Siu, Lam, & Chan, 2012; Torres, Hoff, Padovani, & Ramos-Cerqueira, 2012). Furthermore, a longer duration of OCD illness and presence of comorbid depression in the caregiver are also predictive of lower perceived QoL (Cicek, Cicek, Kayhan, Uguz, & Kaya,

2013). It is unclear what the direction of causality is between depression and duration of illness, though the relationship is likely bidirectional; a longer duration of coping with the illness may lead to increased helplessness and depressive symptoms, while increased depressive symptoms can also lead to amotivation and decreased ability to support the patient with OCD.

Family burden for caregivers of adults with OCD is comparable to burden levels experienced by caregivers of schizophrenic patients (Grover & Dutt, 2011; Gururaj, Bada Math, Reddy, & Chandrashekar, 2008; Kalra, Nischal, Trivedi, Dalal, & Sinha, 2009; Negm, Mahdy, Khashaba, & Abd El-Latif, 2014; Thomas, Suresh Kumar, Verma, Sinha, & Andrade, 2004). Furthermore, levels of caregiver burden are even higher when compared to the burden experienced by caregivers of depressed patients (Vikas et al., 2011) and matched (healthy) controls (Cicek et al., 2013; Verma & Sinha, 2013). Increased family accommodation is also linked to increased caregiver burden (Gururaj et al., 2008; Ramos-Cerqueira, Torres, Torresan, Negreiros, & Vitorino, 2008; Siu et al., 2012; Torres et al., 2012), as these behaviors place additional strain on the caregiver by requiring added effort and time spent on accommodating the OCD symptomology. Additionally, caregiver psychiatric comorbidity (especially comorbid depression) and the patient's concurrent depressive symptoms both contribute to increased caregiver burden (Cicek et al., 2013; Ramos-Cerqueira et al., 2008; Torres et al., 2012). A longer course of OCD and poorer patient insight into OCD symptomology are also predictive of heightened caregiver burden (Cicek et al., 2013). Furthermore, individuals with low insight lack the ability to recognize the excessive and unreasonable nature of their symptoms, requiring additional family involvement (Bipeta, Yerramilli, Pingali, Karredla, & Ali, 2013; Storch, Milsom, et al., 2008; Wu & Lewin, in press), and thereby incurs higher levels of burden.

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 surprising that there has not been equal attention spent on examining caregiver burden and QoL in pediatric OCD. This is a troubling gap in the research, as the experiences of caregivers for adults versus youth are qualitatively different (de Oliveira et al., 2014). Previous studies have focused exclusively on the youth, elucidating the negative impact of the disorder on the child's own QoL (Lack et al., 2009), but there have unfortunately 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. Geffken et al. (2006) investigated the link between hope, coping techniques, and depressive symptoms. Results indicated that hope, active reframing of the situation, and increased coping through social supports were negatively correlated with depressive symptoms. Additionally, Derisley, Libby, Clark, and Reynolds (2005) found that parents of youth with OCD more commonly used avoidant coping strategies when compared to parents of healthy controls. This is problematic, as coping plays a meditational role in the relationship between hope and depressive symptoms (Geffken et al., 2006). These findings are corroborated by results from the physical illness literature (Khalaila & Litwin, 2011; Papastavrou et al., 2011), as the type of coping style can negatively influence the parents' mental health.   Furthermore, the mental health of parents of youth with OCD is lower than the mental health of parents of healthy controls (Derisley et al., 2005), although Storch et al. (2009) did not find a significant correlation between OCD symptom severity and parental psychopathology.

There has only been one study to date that has examined the parental experience and strain of caring for a child with OCD (Storch et al., 2009). Parents reported considerable distress regarding the child's illness, and increased OCD symptom severity and impairment were related to uncertainty and worry about the child's condition. Additionally, 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.

Present Study

Surprisingly, there have been no studies to date that directly examine the QoL of the caregiver of a child with OCD. This is highly problematic, given the salience of family accommodation and continued enmeshment of the caregivers with the OCD symptomology. Additionally, only one study to date has investigated the construct of caregiver strain in pediatric OCD, necessitating more nuanced investigations into potential factors that may contribute to increased burden. Furthermore, there have been no studies examining these constructs in a more severe OCD sample, highlighting the importance of considering youth needing intensive treatment for their OCD symptoms. These youth are of particular interest, as children seeking intensive treatment for OCD are often treatment refractory (Marien, Storch, Geffken, & Murphy, 2009) and typically present with more severe OCD symptoms (Franklin et al., 1998; Franklin,

Tolin, March, & Foa, 2001; Whiteside & Jacobsen, 2010). Unfortunately, higher baseline OCD symptom severity is predictive of poorer treatment outcomes (Ginsburg, Kingery, Drake, & Grados, 2008; Piacentini, Bergman, Jacobs, McCracken, & Kretchman, 2002; Stewart, Yen, Stack, & Jenike, 2006), likely compounding the familial impact and exacerbating family involvement in the symptomology.

Given the lack of investigations within the realm of pediatric OCD, this study seeks to elucidate this gap in research by investigating caregiver QoL and burden in a pediatric OCD sample receiving treatment from a specialized intensive/partial hospitalization outpatient facility. Given the limitations in extant literature, this study's aims and hypotheses are as follows:

Hypothesis 1/Specific Aim 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 are expected to be correlated with lower caregiver QoL and higher caregiver burden (Albert et al., 2007; Gururaj et al., 2008; Ramos-Cerqueira et al., 2008; Siu et al., 2012).

Hypothesis 2/Specific Aim 2. Investigate the correlation between OCD symptom severity and family variables (i.e., general family functioning, parental relationship, and positive aspects of caregiving). More severe OCD symptoms are expected to be associated with a negative impact on the family's overall functioning and the relationship between the caregivers (Black et al., 1998). Although positive aspects of caregiving have yet to be studied in patients with OCD, 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 (Tarlow et al., 2004).

Hypothesis 3/Specific Aim 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 correlated with caregiver QoL and positively correlated with caregiver burden (Black et al., 1998; Ramos-Cerqueira et al., 2008; Storch et al., 2009).

Given the nascent nature of the literature in this domain, there are unfortunately limited studies available to inform power analyses for more sophisticated statistical procedures. However, based on the impact of caregiver and youth comorbidities on caregiver well-being (Cicek et al., 2013; Storch et al., 2009), the following exploratory aims are proposed:

Exploratory Aim 1. Determine if comorbid anxiety or depressive symptoms in the caregiver contribute to poorer caregiver QoL and higher caregiver burden, beyond the effects of OCD symptom severity. Although Cicek et al. (2013) did not control for OCD symptom severity, their results suggested that comorbid depression in caregivers was predictive of their QoL. Based on these findings, anxiety and depressive symptoms in the caregiver are expected to predict caregiver QoL and burden, above and beyond the effects of OCD symptom severity.

Exploratory Aim 2. Determine if internalizing or externalizing symptoms in the youth contribute to poorer caregiver QoL and higher caregiver burden, beyond the effects of OCD symptom severity. Internalizing symptoms are predictive of parental distress (Storch et al., 2009), but it is still unclear if their impact is unique or mostly attributable to the OCD symptoms. While there is limited literature on this relationship, the impactful and complicating nature of comorbid symptomology in OCD patients (Huppert, Simpson, Nissenson, Liebowitz, & Foa, 2009; Storch, Lewin, Geffken, Morgan, & Murphy, 2010; Storch, Merlo, et al., 2008) lead to the

expectation that internalizing and externalizing symptoms in youth will predict poorer caregiver QoL and higher burden, even after controlling for OCD symptom severity.

Exploratory Aim 3. 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 (Haley et al., 1987; Haley et al., 1996; Schulz et al., 1995), the perceived burden may mediate the relationship between OCD symptom severity and caregiver QoL.

METHOD

Participants

Participants included 72 youth and caregiver dyads (see Analytic Plan for power analysis). 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 ($SD = 3.52$) with a range from 2-15 years of age, as well as a reported mean age of diagnosis at 10.93 years ($SD = 3.10$) with a range from 5-16 years of age. Caregivers were mostly mothers ($n = 57$), with some father ($n = 7$) and other caregiver ($n = 8$) participation. The majority of caregivers reported an annual income of over $150,000 or more ($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 in study procedures. The diagnosis for OCD was determined through the regular intake procedures for Rogers, which included the gold standard clinician-rated interview for OCD symptoms, as well as clinical consensus of meeting DSM-5 criteria for OCD through clinical interactions with the patient and data from self-report questionnaires (American Psychiatric Association, 2013; Leckman, Sholomskas, Thompson, Belanger, &

Weissman, 1982; Storch et al., 2012). Specifically, two experienced psychologists, one board certified medical doctor, and the principal investigator of the study (M.S.W.) met to review each case for inclusion.

Procedures

The study underwent the University of South Florida institutional review board (IRB) and the Rogers Memorial Hospital IRB prior to starting participant enrollment. Potential participants were provided a copy of the informed consent (caregivers) and assent (youth with OCD) documents, and a clinic staff member reviewed it with the family in detail. All questions and concerns were addressed prior to study participation, and families were provided with additional time if desired to further consider potential participation. It was emphasized that participation in the study is entirely voluntary, and their decision to participate or not to participate did not affect their treatment status at Rogers in any way.

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. As the clinician-rated measure assessing OCD symptom severity is already included as part of their routine clinical care at Rogers, the consent requested to have those scores extrapolated for study use to reduce subject burden. Additionally, all families were enrolled for the study within the first week of care to ensure that the timeframes of the assessment battery were consistent. Clinician-administered measures were administered first, followed by self-report measures. Self-report measures were ordered based on the following conceptual groupings (from first to last): OCD-related impairment, caregiver quality of life and burden, family variables (i.e., positive aspects of caregiving, family functioning, and relationship quality), comorbid psychopathology,

and general demographics. All other clinician- and self-report measures took around 30 to 45

minutes of the family's time. Consent and clinician-administered interviews were conducted by

doctoral staff and the study principal investigator (M.S.W.).

   To ensure inter-rater reliability for clinician-rated interviews, all raters were required to

match to a gold-standard audiotape prior to administering any of the clinician-rated measures.

Thereafter, an additional rater was planned to be present for 20% of the initial interview for

assessing obsessive-compulsive symptom severity, but given clinic staff shortages and feasibility

barriers (e.g., clinic policy did not permit audiotaping of interviews), these circumstances only

allowed for 7% ($n = 5$) of cross-ratings. It is noted that each case was discussed at a weekly case

conference and difficult cases were discussed outside of the case conferences to help facilitate

more accurate scoring. Total scores were compared for inter-rater reliability.

Measures

   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. The first section contains a symptom checklist and assesses

the presence of various obsessive-compulsive symptom clusters (e.g., contamination, aggressive,

magical/superstitious). 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 (i.e., sum of the obsessions and compulsions severity scales). Responses on the severity

scale are scored on a Likert scale from 0 to 4, with higher scores indicating more severe OCD

symptoms. The CY-BOCS total score exhibits high internal consistency, good to excellent inter-

rater reliability, satisfactory convergent and divergent validity (Scahill et al., 1997; Storch et al.,

2004), as well as treatment sensitivity (Storch, Lewin, De Nadai, & Murphy, 2010; The Pediatric

OCD Treatment Study (POTS) Team, 2004).

For the present study, the inter-rater reliability for the Obsession Severity scale was

excellent (ICC = .99, 95% CI [.93,1.00]). The reliability for the Compulsion Severity scale was

excellent as well (ICC = .95, 95% CI [.40, .99]), and the reliability for the Total Severity scale

was excellent (ICC = .99, 95% CI [.92, 1.00]). The Cronbach's α's for the present sample were

.89 for the Total Severity scale, .82 for the Obsession Severity scale, and .76 for the Compulsion

Severity scale.

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 in the previous

week. The questions are directed at the relative accommodating the patient with OCD, covering

a broad range of potential accommodations (e.g., providing reassurance, facilitating avoidance,

taking on the patient's responsibilities). The FAS-IR response items are provided on scale from

0 to 4, with 0 meaning "*None*" and 4 meaning that the accommodating behavior occurred

"*Everyday.*" The measure provides a total score by summing all of the items, with higher scores

indicating more symptom accommodation. The FAS-IR total score has exhibited good

agreement across raters, convergent and divergent validity, and internal consistency

(Calvocoressi et al., 1999). Cronbach's α for the present sample was .87 for the total score.

Caregiver Burden Inventory (CBI). The CBI (Novak & Guest, 1989) is a 24-item

caregiver self-report questionnaire that assesses multiple dimensions of caregiver burden.

Responses are provided on a scale from 0 to 4, with 0 meaning "Never" and 4 meaning "Nearly

Always." Reflecting the multidimensionality of burden, the items on the CBI form 5 subscales:

Time Dependency (e.g., "I have to help him/her with many basic functions), Development (e.g.,

"I feel that I am missing out on life"), Physical Health (e.g., "I'm not getting enough sleep"),

Emotional Health (e.g., "I resent him/her"), and Social Relationships (e.g., "My care giving

efforts aren't appreciated by others in my family"). 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 (Chou, Jiann-Chyun, & Chu, 2002; Küçükgüçlü, Esen, & Yener,

2009; Novak & Guest, 1989). The Cronbach's α's for the present sample were .91 for the total

score and .81 – .91 for the subdomains.

World Health Organization Quality of Life – BREF (WHOQOL-BREF). The

WHOQOL-BREF (The WHOQOL Group, 1998) is a 26-item self-report questionnaire that

assesses the respondent's quality of life in the previous four weeks. Item responses are provided

on a Likert scale from 1 to 5, with lower scores indicating poorer quality of life. Total scores can

be garnered across four life domains: Physical Health, Psychological, Social Relationships, and

Environment. Total scores are then transformed to allow for comparisons to other validated QoL

instruments, such as the full 100-question version of the measure. The respondent's overall

perception of their QoL is also acquired through one question (non-transformed). The

WHOQOL-BREF demonstrates good internal consistency, test-retest reliability, content validity,

discriminant validity, and construct validity (Skevington, Lotfy, O'Connell, & WHOQOL Group,

2004; The WHOQOL Group, 1998). Additionally, this measure has been validated extensively

across various cultures and multiple samples of families with OCD (Cicek et al., 2013; Grover &

Dutt, 2011; Gururaj et al., 2008; Stengler-Wenzke et al., 2006; Vikas et al., 2011). The

Cronbach's α's for the present sample were .67 – .88 for the subdomains.

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, and respondents will be explicitly asked to focus on impairment directly related to

the youth's OCD symptoms. Responses are provided on a scale from 0 to 10, with 0 meaning

"*not at all*" and 10 meaning "*extremely*." Items can be considered individually or 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

(Hambrick, Turk, Heimberg, Schneier, & Liebowitz, 2004; Mendlowicz & Stein, 2000). The

Cronbach's α for the present sample was .73 for the total score (both parent- and child-report

versions).

Family Assessment Device – 12-Item Version (FAD-12). The FAD-12 (Epstein, Baldwin,

& Bishop, 1983) is a 12-item self-report questionnaire that assesses general family functioning.

Respondents provide their level of agreement with each provided statement, with the choices of

"*strongly agree*," "*agree*," "*disagree*," or "*strongly disagree*." A total score is garnered from

summing the items (with certain items reverse scored), and higher scores indicate poorer family

functioning (Ryan, Epstein, Keitner, Miller, & Bishop, 2005). 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 (Barrett, Healy-Farrell, & March, 2004;

Calvocoressi et al., 1999; Pinto, Van Noppen, & Calvocoressi, 2013). This truncated version of

the FAD measure will help reduce subject burden and allow score comparisons across previous

studies. Additionally, the scores on the General Functioning subscale had the highest internal

consistency out of all of the FAD subscales, are equipped to differentiate between clinical and

nonclinical populations (Epstein et al., 1983), and demonstrate good validity and reliability

(Byles, Byrne, Boyle, & Offord, 1988). The Cronbach's α for the present sample was .95 for the

total score.

Couples Satisfaction Index – 16 (CSI-16). The CSI-16 is a 16-item self-report

questionnaire that examines the relationship quality of a romantically linked dyad. The parent

will be filling this out about their overall satisfaction with their partner. All items are provided

on a Likert scale, with higher scores indicating higher satisfaction with the relationship. The

CSI-16 is an abbreviated version of the CSI-32, and selectively retains the items that provide the

most information about relationship quality. The CSI-16 total score demonstrates excellent

convergent and construct validity, as well as precision in assessing varying levels of couples'

satisfaction (Funk & Rogge, 2007). Given the content of the questionnaire, only participants

with a romantic partner were asked to fill out a CSI-16 ($n = 57$) for the present study. The

Cronbach's α for the present sample was .99 for the total score.

Positive Aspects of Caregiving. The Positive Aspects of Caregiving measure (Tarlow et

al., 2004) is a 9-item measure 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 (Tarlow et al., 2004). The

Cronbach's α's for the present sample were .87 for the total score and .86 - .88 for the subscales.

Depression Anxiety Stress Scale – Short Version (DASS21). The DASS21 (Lovibond &

Lovibond, 1995) is a 21-item self-report questionnaire that assesses the presence and severity of

stress, anxiety, and depressive symptoms in the past week. Responses can be provided on a

Likert scale from 0 to 3, with 0 meaning "*Did not apply to me at all*," and 3 meaning "*Applied to*

me very much, or most of the time." Subscale scores can be calculated for anxiety, stress, and

depressive symptoms separately, or a total score can be calculated by summing all items, with

higher scores indicating more severe symptoms. These scores are subsequently doubled to

parallel the scores and norms garnered from the original DASS measure. Although the DASS21

contains half of the items of the original DASS measure, comparable item means have been

calculated and both measures share similar factor structures. Additionally, the DASS21 has

demonstrated adequate to excellent internal consistency, as well as concurrent validity (Antony,

Bieling, Cox, Enns, & Swinson, 1998).   The DASS21 scores possess treatment sensitivity, as

well as convergent validity with measures examining patient functioning (Ng et al., 2007). The

Cronbach's α for the present sample was .73 for the anxiety subscale and .92 for the depression

subscale.

Child Behavior Checklist (CBCL). The CBCL is a 113-item parent-report questionnaire

that assesses the presence and severity of emotional and/or behavioral problems in youth.

Parents can respond on a scale from 0 to 2, with 0 meaning "*Not True*," 1 meaning "*Somewhat or*

Sometimes True," and 2 meaning "*Very True or Often True*." For the purposes of this study, the

Internalizing and Externalizing subscales of the CBCL are of particular interest. The CBCL

scores have demonstrated excellent inter-parent agreement, test-retest reliability (Achenbach &

Edelbrock, 1981), and the diagnostic scale scores exhibit good discriminant and convergent

validity, along with good reliability (Nakamura, Ebesutani, Bernstein, & Chorpita, 2009). The

Cronbach's α for the present sample was .91 for both the internalizing and the externalizing

subscales.

A brief demographics questionnaire was administered to garner basic sociodemographic

information such as age, gender, ethnicity, and annual household income. Information regarding

the age at diagnosis and emergence of obsessive-compulsive symptoms were also included. A

full list of the measures is included in Table 1.

Analytic Plan

The target sample size was determined *a priori* via the G*Power application (Faul,

Erdfelder, Buchner, & Lang, 2009); with a two-tailed alpha level of .05 and power set at .80,

approximately 61 caregivers were needed to be recruited in order to detect correlations $\geq .35$.

Pearson product-moment correlations were calculated to determine the linear relationships

between caregiver burden/QoL and variables of interest. Correlations greater than or equal to

.01, .03, and .05 were considered "small," "medium," and "large" based on criteria suggested by

(J. Cohen, 1988). By determining which variables were correlated with caregiver QoL and

burden, these data will help elucidate specific factors that may negatively impact caregivers and

contribute to a more nuanced understanding of QoL and burden. For the exploratory analyses,

hierarchical multiple regressions were conducted to determine unique predictors of caregiver

QoL and burden. Specifically, these analyses were hoped to help clarify the impact of comorbid

psychopathology, beyond the effects of obsessive-compulsive symptom severity. To examine

the mediational model, the INDIRECT macro in SPSS was employed as described by Preacher

and Hayes (2008); this method allows for testing of the specific mediational effect with higher

power due to bootstrapped resampling (Hayes, 2009). Bootstrap resamples were set to 5,000 and

mediators were interpreted as statistically significant if their 95% CI did not include 0. To

determine inter-rater reliability on the CY-BOCS, the intraclass correlation coefficient (ICC) was

calculated within a two-way random effects model, measuring absolute agreement.

Regarding missing data, the most common reason was due to caregivers and/or youths

being unwilling to complete their respective self-report questionnaires ($n = 12$; most frequently

due to perceived burden, as they were primarily at Rogers to receive intensive treatment for

OCD). 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 less than 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 2-5 for the exact number of participants that

completed each respective measure.

Design Considerations

A single time point study was employed based on considerations of the study aims and

potential subject burden. Correlational analyses and hierarchical multiple regressions can be

conducted from cross-sectional studies. Additionally, given that Rogers is primarily a clinical

setting, research assessments beyond the standard of care may be burdensome for families,

resulting in the decision to have a single time point study. Additionally, although inter-rater

reliability is typically conducted post hoc with audio recordings, limitations in recruiting from a

primarily clinical setting apply, resulting in the decision to have live inter-rater ratings.

Only one caregiver was in attendance for the assessment, and the participating caregiver was chosen based on the individual that is most (1) knowledgeable about the symptomology and (2) involved with the youth's OCD. This was also to ensure consistency of the number of reporters across dyads, as not all families presented consistently with both caregivers; restricting assessments to one caregiver permitted comparability across responses.

RESULTS

Caregiver QoL and Burden and OCD-Related Variables

Pearson correlations were not significant when examining the relationship between caregiver QoL (both total score and across subdomains) and child OCD symptom severity (CY-BOCS total), $ps > .05$. Parent-rated functional impairment related to child's OCD (SDS-P total) only demonstrated a small, negative correlation with overall caregiver QoL (WHOQOL-BREF #1). Child-rated OCD-related impairment (SDS-C total) was not correlated with any caregiver QoL variables, $ps > .05$. Family accommodation (FAS total) demonstrated a small, negative correlation with caregiver psychological well-being, but it was not associated with any other caregiver QoL variables. The duration of the child's OCD symptoms did not have a statistically significant correlation with caregiver QoL.

For caregiver burden, child obsessive-compulsive symptom severity possessed a positive, medium correlation with the time dependency domain of caregiver burden. Parent-rated OCD-related impairment possessed positive, medium correlations with total caregiver burden and development burden, small correlations with burdens related to social relationships and emotional health, as well as a large correlation with time dependency. Child-rated OCD-related impairment showed a positive, medium correlation with caregiver time dependency. Family accommodation demonstrated medium, positive correlations with total caregiver burden and the burden subdomains of development and social relationships. Family accommodation also exhibited a large, positive correlation with time dependency. The duration of the child's OCD

symptoms did not have a statistically significant correlation with caregiver burden. To view the full table of correlations for caregiver QoL and burden, please see Tables 2 and 3.

Child OCD Symptoms and Family Variables

Child obsessive-compulsive symptom severity was not statistically significantly correlated with any of the family variables, which included general family functioning (FAD total), caregiver romantic relationships (CSI total), and positive aspects of caregiving (PAoC total and subdomains of self-affirmation and outlook on life), $ps > .05$. Please see Table 4 to view the full correlational matrix.

Caregiver QoL and Burden and Comorbid Psychopathology

With regards to caregiver QoL, caregiver anxiety symptoms had a small, negative correlation with environment-related QoL, also demonstrating medium, negative correlations with physical and psychological well-being. However, caregiver depressive symptoms demonstrated statistically significant, negative correlations with all aspects of caregiver QoL. Youth internalizing symptoms did not correlate with caregiver QoL. However, youth externalizing symptoms demonstrated a small, negative relationship with overall caregiver QoL. The full correlational matrix can be viewed in Table 2. Of note, independent sample t tests did not reveal any gender differences on youth internalizing symptoms, $t(62) = -0.11, p = .91$, nor externalizing symptoms, $t(62) = 0.38, p = .70$.

Regarding caregiver burden, caregiver anxiety symptoms demonstrated positive, medium correlations with total caregiver burden and burden on social relationships. Caregiver depressive symptoms demonstrated statistically significant correlations with all aspects of caregiver burden

except for the time dependency domain. Youth internalizing symptoms exhibited a small,

positive correlation with total caregiver burden and a medium, positive correlation with time

dependency. Youth externalizing symptoms possessed statistically significant correlations with

all caregiver burden variables, except for those related to physical health and social relationships.

The full correlational matrix can be viewed in Table 3.

Predicting Caregiver QoL and Burden with Comorbid Psychopathology

Results from the respective hierarchical regressions are in Table 6. Youth (internalizing

and externalizing symptoms) and caregiver (anxiety and depressive symptoms) psychopathology

were examined as potential predictors of caregiver QoL, after controlling for obsessive-

compulsive symptom severity. Variance inflation factor (VIF) values stayed < 2 for the

variables, indicating low correlations between the variables of interest. Given that all tolerance

values were greater than or equal to .50 as well, the collective data did not raise notable concerns

for multicollinearity and the regression was conducted thereafter (Mansfield & Helms, 1982;

Menard, 1995). In the first step of the hierarchical multiple regression, obsessive-compulsive

symptom severity was not a significant predictor of caregiver QoL, $F(1, 59) = 0.04$, $p = .85$.

When considering youth and caregiver psychopathology in the second step of the regression,

only caregiver depressive symptoms emerged as a statistically significant predictor of caregiver

QoL, $F(4, 55) = 5.34$, $p = .001$, with this model accounting for about 28% 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 obsessive-compulsive symptom severity, youth (internalizing and

externalizing symptoms) and caregiver (anxiety and depressive symptoms) were examined as

potential predictors of caregiver burden. VIF values ranged between $1 - 2$ for the variables, indicating low correlations between the variables of interest. Given that all tolerance values were greater than or equal to .50, these collective data supported continuing with a regression to analyze these relationships. In the first step, obsessive-compulsive symptom severity again did not emerge as a statistically significant predictor of caregiver burden, $F(1, 57) = 1.48$, $p = .23$. In the second step of the regression, this model accounted for 36% of the variance in caregiver burden, $F(4, 53) = 7.91$, $p < .001$. However, only youth externalizing behaviors and caregiver depressive symptoms emerged as significant predictors, indicating that these comorbid symptoms are linked with higher levels of caregiver burden.

Mediational Model

Caregiver burden was tested as a potential mediator for the relationship between child OCD symptom severity and caregiver QoL. The path (a) from child OCD symptom severity to caregiver burden was not statistically significant, $\beta = 0.43$, $t(60) = 1.19$, $p = .24$. The direct effect of caregiver burden on caregiver QoL (b path) was statistically significant, $\beta = -0.04$, $t(60) = -7.27$, $p < .001$. The total effect of OCD symptom severity on caregiver QoL was not significant, $\beta = 0.03$, $t(60) = 0.14$, $p = .89$. Lastly, the direct effect of child OCD symptom severity on caregiver QoL was not significant, $\beta = 0.02$, $t(60) = 1.30$, $p = .20$. Ultimately, caregiver burden was not found to mediate the relationship between child OCD symptom severity and caregiver QoL ($\beta = -0.02$, 95% CI [-0.05, 0.01]).

DISCUSSION

Given the paucity of studies examining caregiver QoL and burden in childhood OCD, this study sought to elucidate potential relationships between these phenomena and relevant clinical variables. 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 that are indirectly impacting caregiver QoL. For instance, obsessive-compulsive symptoms leading to decreased school functioning or poorer completion of daily tasks may lead to worse caregiver QoL, which is reflected in the link between higher impairment and lower 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 impactful for the 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 (Wu et al., 2014). 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, relationship satisfaction, 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 (Wu et al., 2016). Additionally, given that youths in this study were presenting for intensive outpatient or partial hospitalization levels of treatment, the sample may have been limited (and skewed) towards the more severe end of the distribution; this could have precluded the ability to observe a correlation due to the limited variance and restriction of range in the CY-BOCS scores. Lastly, it is also quite possible that these family variables are not linked with obsessive-compulsive symptom severity. Additional variables could be moderating these relationships, so the impact of extraneous variables should be examined in further studies. For instance, positive aspects of caregiving may only be observed in families that have positive coping skills and can manage the symptomology in an adaptive manner. 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 (Stewart et al., 2011).

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. With 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 (Ergh, Rapport, Coleman, & Hanks, 2002; Haley et al., 1987). Indeed, these caregivers are already comparatively experiencing more burden than caregivers of those with elderly dementia (Marvardi et al., 2005) or early psychosis (McCleery, Addington, & Addington, 2007), reflecting the importance of ensuring the appropriate supports are in place. Additionally, symptoms of anxiety could be targeted to ameliorate avoidant and other maladaptive coping 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, reflecting their salient impact. Furthermore, depressive symptoms independently predicted caregiver QoL and also predicted burden, highlighting the robust and deleterious effects of experiencing these symptoms (Cicek et al., 2013). 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. Until further prospective studies clarify these dynamics, 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 (Ramos-Cerqueira et al., 2008), 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 (Lebowitz, 2013), especially given the known interplay between rage outbursts/behavioral difficulties and increased OCD-related functional impairment (Storch et al., 2012).

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 (Haley et al., 1987; Haley et al., 1996; Schulz & Beach, 1999). 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.

These findings should be interpreted within the context of several limitations. First, the study was cross-sectional in nature, so the directionality of the effects and causality of the variables cannot be ascertained within this design. 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). Future studies are encouraged to investigate the longitudinal effects of OCD-related burden on caregivers and better establish the temporal model of this relationship. Second, most participants were upper-middle class Caucasian families, potentially limiting the generalizability 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 (Phares & Compas, 1992). 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 (Settineri et al., 2014). Indeed, the caregivers in the present study fell around 1 SD below norms for their mean psychological well-being and social relationships (Hawthorne, Herrman, & Murphy, 2006), and above the 70th/80th percentile for their anxiety/depressive symptoms, on average (Crawford & Henry, 2003). Additionally, given the higher rates of caregiver psychopathology in this sample, future studies may consider the potential impact of parental psychopathology on the perception of child symptomology (Jensen, Traylor, Xenakis, & Davis, 1988). 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, future studies should examine alternative models for interpreting the interplay of child and caregiver psychopathology on caregiver QoL/burden. For instance, it would be interesting to examine whether caregiver experiences are impacted after controlling for their own psychopathology, testing whether or not child psychopathology affects caregiver QoL/burden beyond the caregiver's own symptoms. Seventh, 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) would be important to examine to determine cumulative effects that may impact caregiver QoL/burden.

Ultimately, considering the lack of research on the QoL and burden of caregivers of youth with OCD, this study functions as the first investigation of these joint constructs in a pediatric sample. Much of the attention has understandably been devoted to the functional

impact and diminished QoL of the child with OCD. However, given the enmeshment and inevitable impact of the disorder on caregivers, it is imperative to consider the expansive consequences of the illness on the immediate family as well. 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 deleterious 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, these data are hoped to help identify at-risk families and inform more targeted interventions.

REFERENCES

Achenbach, T. M., & Edelbrock, C. S. (1981). Behavioral problems and competencies reported by parents of normal and disturbed children aged four through sixteen. *Monographs of the Society for Research in Child Development*, 1-82.

Albert, U., Bogetto, F., Maina, G., Saracco, P., Brunatto, C., & Mataix-Cols, D. (2010). Family accommodation in obsessive-compulsive disorder: Relation to symptom dimensions, clinical and family characteristics. *Psychiatry Research, 179*(2), 204-211. doi: 10.1016/j.psychres.2009.06.008

Albert, U., Salvi, V., Saracco, P., Bogetto, F., & Maina, G. (2007). Health-related quality of life among first-degree relatives of patients with obsessive-compulsive disorder in Italy. *Psychiatric Services, 58*(7), 970-976. doi: 10.1176/appi.ps.58.7.970

American Academy of Child and Adolescent Psychiatry. (2012). Practice parameters for the assessment and treatment of children and adolescents with obsessive-compulsive disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(1), 98-113.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Amir, N., Freshman, M., & Foa, E. (2000). Family distress and involvement in relatives of obsessive-compulsive disorder patients. *Journal of Anxiety Disorders, 14*(3), 209-217.

Antony, M. M., Bieling, P. J., Cox, B. J., Enns, M. W., & Swinson, R. P. (1998). Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychological Assessment, 10*, 176-181. doi: 10.1037/1040-3590.10.2.176

Armstrong, D., Lycett, K., Hiscock, H., Care, E., & Sciberras, E. (2014). Longitudinal associations between internalizing and externalizing comorbidities and functional outcomes for children with ADHD. *Child Psychiatry and Human Development, 46*(5), 736-748. doi: 10.1007/s10578-014-0515-x

Awad, A. G., & Voruganti, L. N. (2008). The burden of schizophrenia on caregivers: a review. *Pharmacoeconomics, 26*(2), 149-162.

Barrett, P. M., Healy-Farrell, L., & March, J. S. (2004). Cognitive-behavioral family treatment of childhood obsessive-compulsive disorder: A controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry, 43*(1), 46-62. doi: 10.1097/01.chi.0000096367.43887.13

Bipeta, R., Yerramilli, S. S., Pingali, S., Karredla, A. R., & Ali, M. O. (2013). A cross-sectional study of insight and family accommodation in pediatric obsessive-compulsive disorder. *Child and Adolescent Psychiatry and Mental Health, 7*(20). doi: 10.1186/1753-2000-7-20

Black, D. W., Gaffney, G., Schlosser, S., & Gabel, J. (1998). The impact of obsessive-compulsive disorder on the family: preliminary findings. *Journal of Nervous and Mental Disease, 186*(7), 440-442.

Byles, J., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario Child Health Study: reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Family Process, 27*(1), 97-104.

Calvocoressi, L., Lewis, B., Harris, M., Trufan, S. J., Goodman, W. K., McDougle, C. J., & Price, L. H. (1995). Family accommodation in obsessive-compulsive disorder. *American Journal of Psychiatry, 152*, 441-443.

Calvocoressi, L., Mazure, C. M., Kasl, S. V., Skolnick, J., Fisk, D., Vegso, S. J., . . . Price, L. H. (1999). Family accommodation of obsessive-compulsive symptoms: instrument development and assessment of family behavior. *Journal of Nervous and Mental Disease, 187*(10), 636-642.

Caporino, N. E., Morgan, J., Beckstead, J., Phares, V., Murphy, T. K., & Storch, E. A. (2012). A structural equation analysis of family accommodation in pediatric obsessive-compulsive disorder. *Journal of Abnormal Child Psychology, 40*(1), 133-143. doi: 10.1007/s10802-011-9549-8

Caqueo-Urizar, A., Gutierrez-Maldonado, J., & Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: a literature review. *Health and Quality of Life Outcomes, 7*, 84. doi: 10.1186/1477-7525-7-84

Cherian, A. V., Pandian, D., Bada Math, S., Kandavel, T., & Janardhan Reddy, Y. C. (2014). Family accommodation of obsessional symptoms and naturalistic outcome of obsessive-compulsive disorder. *Psychiatry Research, 215*(2), 372-378. doi: 10.1016/j.psychres.2013.11.017

Chou, K. R., Jiann-Chyun, L., & Chu, H. (2002). The reliability and validity of the Chinese version of the caregiver burden inventory. *Nursing Research, 51*(5), 324-331.

Cicek, E., Cicek, I. E., Kayhan, F., Uguz, F., & Kaya, N. (2013). Quality of life, family burden and associated factors in relatives with obsessive-compulsive disorder. *General Hospital Psychiatry, 35*(3), 253-258. doi: 10.1016/j.genhosppsych.2013.01.004

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*(2), 184-188.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Cooper, M. (1996). Obsessive-compulsive disorder: Effects on family members. *American Journal of Orthopsychiatry, 66*(2), 296-304.

Crawford, J. R., & Henry, J. D. (2003). The Depression Anxiety Stress Scales (DASS): Normative data and latent structure in a large non-clinical sample. *British Journal of Clinical Psychology, 42*(2), 111-131. doi: 10.1348/014466503321903544

de Oliveira, G. R., Neto, J. F., de Camargo, S. M., Lucchetti, A. L., Espinha, D. C., & Lucchetti, G. (2014). Caregiving across the lifespan: comparing caregiver burden, mental health, and quality of life. *Psychogeriatrics*. doi: 10.1111/psyg.12087

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. *British Journal of Clinical Psychology, 44*(Pt 3), 439-444. doi: 10.1348/014466505x29152

Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy, 9*(2), 171-180.

Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation, 17*(2), 155-174.

Fadden, G., Bebbington, P., & Kuipers, L. (1987). The burden of care: The impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry, 150*, 285-292.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*(4), 1149-1160. doi: 10.3758/brm.41.4.1149

Ferrao, Y. A., Shavitt, R. G., Bedin, N. R., de Mathis, M. E., Carlos Lopes, A., Fontenelle, L. F., . . . Miguel, E. C. (2006). Clinical features associated to refractory obsessive-compulsive disorder. *Journal of Affective Disorders, 94*(1-3), 199-209. doi: 10.1016/j.jad.2006.04.019

Foldemo, A., Gullberg, M., Ek, A. C., & Bogren, L. (2005). Quality of life and burden in parents of outpatients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 40*(2), 133-138. doi: 10.1007/s00127-005-0853-x

Franklin, M. E., Kozak, M. J., Cashman, L. A., Coles, M. E., Rheingold, A. A., & Foa, E. B. (1998). Cognitive- behavioral treatment of pediatric obsessive- compulsive disorder: An open clinical trial. *Journal of the American Academy of Child & Adolescent Psychiatry, 37*(4), 412-419.

Franklin, M. E., Tolin, D. F., March, J. S., & Foa, E. B. (2001). Treatment of pediatric obsessive-compulsive disorder: A case example of intensive cognitive-behavioral therapy involving exposure and ritual prevention. *Cognitive and Behavioral Practice, 8*(4), 297-304. doi: http://dx.doi.org/10.1016/S1077-7229(01)80002-X

Funk, J. L., & Rogge, R. D. (2007). Testing the ruler with item response theory: increasing precision of measurement for relationship satisfaction with the Couples Satisfaction Index. *Journal of Family Psychology, 21*(4), 572-583. doi: 10.1037/0893-3200.21.4.572

Futh, A., Simonds, L. M., & Micali, N. (2012). Obsessive-compulsive disorder in children and adolescents: parental understanding, accommodation, coping and distress. *Journal of Anxiety Disorders, 26*(5), 624-632. doi: 10.1016/j.janxdis.2012.02.012

Gater, A., Rofail, D., Tolley, C., Marshall, C., Abetz-Webb, L., Zarit, S. H., & Berardo, C. G. (2014). "Sometimes it's difficult to have a normal life": Results from a qualitative study exploring caregiver burden in schizophrenia. *Schizophrenia Research and Treatment, 2014*, 368215. doi: 10.1155/2014/368215

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*(5), 614-629. doi: 10.1016/j.janxdis.2005.07.001

Geller, D. A. (2006). Obsessive-compulsive and spectrum disorders in children and adolescents. *Psychiatric Clinics of North America, 29*(2), 353-370. doi: 10.1016/j.psc.2006.02.012

Ginsburg, G. S., Kingery, J. N., Drake, K. L., & Grados, M. A. (2008). Predictors of treatment response in pediatric obsessive-compulsive disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 868-878. doi: 10.1097/CHI.0b013e3181799ebd

Goode, K. T., Haley, W. E., Roth, D. L., & Ford, G. R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology, 17*(2), 190-198.

Gothwal, V. K., Bharani, S., & Mandal, A. K. (2015). Quality of life of caregivers of children with congenital glaucoma: Development and validation of a novel questionnaire (CarCGQoL). *Investigative Ophthalmology & Visual Science*. doi: 10.1167/iovs.14-15905

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. *The Lancet, 281*(7280), 544-547. doi: http://dx.doi.org/10.1016/S0140-6736(63)91339-4

Grover, S., & Dutt, A. (2011). Perceived burden and quality of life of caregivers in obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences, 65*(5), 416-422. doi: 10.1111/j.1440-1819.2011.02240.x

Gururaj, G. P., Bada Math, S., Reddy, J. Y., & Chandrashekar, C. R. (2008). Family burden, quality of life and disability in obsessive compulsive disorder: An Indian perspective. *Journal of Postgraduate Medicine, 54*(2), 91-97.

Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2*(4), 323-330.

Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A., Collins, R. P., & Isobe, T. L. (1996). Appraisal, coping, and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology, 64*(1), 121-129.

Hambrick, J. P., Turk, C. L., Heimberg, R. G., Schneier, F. R., & Liebowitz, M. R. (2004). Psychometric properties of disability measures among patients with social anxiety disorder. *Journal of Anxiety Disorders, 18*(6), 825-839.

Hawthorne, G., Herrman, H., & Murphy, B. (2006). Interpreting the WHOQOL-Brèf: Preliminary population norms and effect sizes. *Social Indicators Research, 77*(1), 37-59. doi: 10.1007/s11205-005-5552-1

Hayes, A. F. (2009). Beyond Baron and Kenny: Statistical mediation analysis in the new millennium. *Communication Monographs, 76*(4), 408-420. doi: 10.1080/03637750903310360

Hoenig, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry, 12*(3), 165-176.

Hsiao, C. Y., & Tsai, Y. F. (2014). Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia. *Journal of Clinical Nursing*. doi: 10.1111/jocn.12745

Hughes, S. L., Giobbie-Hurder, A., Weaver, F. M., Kubal, J. D., & Henderson, W. (1999). Relationship between caregiver burden and health-related quality of life. *Gerontologist, 39*(5), 534-545.

Huppert, J. D., Simpson, H. B., Nissenson, K. J., Liebowitz, M. R., & Foa, E. B. (2009). Quality of life and functional impairment in obsessive-compulsive disorder: a comparison of patients with and without comorbidity, patients in remission, and healthy controls. *Depression and Anxiety, 26*(1), 39-45. doi: 10.1002/da.20506

Jastrowski Mano, K. E., Khan, K. A., Ladwig, R. J., & Weisman, S. J. (2011). The impact of pediatric chronic pain on parents' health-related quality of life and family functioning: reliability and validity of the PedsQL 4.0 Family Impact Module. *Journal of Pediatric Psychology, 36*(5), 517-527. doi: 10.1093/jpepsy/jsp099

Jensen, P. S., Traylor, J., Xenakis, S. N., & Davis, H. (1988). Child psychopathology rating scales and interrater agreement: I. Parents' gender and psychiatric symptoms. *Journal of*

the American Academy of Child and Adolescent Psychiatry, 27(4), 442-450. doi: 10.1097/00004583-198807000-00012

Kalra, H., Nischal, A., Trivedi, J. K., Dalal, P. K., & Sinha, P. K. (2009). Extent and determinants of burden of care in Indian families: A comparison between obsessive-compulsive disorder and schizophrenia. *International Journal of Social Psychiatry, 55*(1), 28-38. doi: 10.1177/0020764008091438

Khalaila, R., & Litwin, H. (2011). Does filial piety decrease depression among family caregivers? *Aging & Mental Health, 15*(6), 679-686. doi: 10.1080/13607863.2011.569479

Krattenmacher, T., Kuhne, F., Halverscheid, S., Wiegand-Grefe, S., Bergelt, C., Romer, G., & Moller, B. (2014). A comparison of the emotional and behavioral problems of children of patients with cancer or a mental disorder and their association with parental quality of life. *Journal of Psychosomatic Research, 76*(3), 213-220. doi: 10.1016/j.jpsychores.2013.11.020

Küçükgüçlü, Ö., Esen, A., & Yener, G. (2009). The reliability and validity of the Caregiver Burden Inventory in Turkey. *Journal of Neurological Sciences (Turkish), 26*(1), 60-73.

Lack, C. W., Storch, E. A., Keeley, M. L., Geffken, G. R., Ricketts, E. D., Murphy, T. K., & Goodman, W. K. (2009). Quality of life in children and adolescents with obsessive-compulsive disorder: base rates, parent-child agreement, and clinical correlates. *Social Psychiatry and Psychiatric Epidemiology, 44*(11), 935-942. doi: 10.1007/s00127-009-0013-9

Laidlaw, T. M., Falloon, I. R., Barnfather, D., & Coverdale, J. H. (1999). The stress of caring for people with obsessive compulsive disorders. *Community Mental Health Journal, 35*(5), 443-450.

Lebowitz, E. R. (2013). Parent-based treatment for childhood and adolescent OCD. *Journal of Obsessive-Compulsive and Related Disorders, 2*(4), 425-431. doi: http://dx.doi.org/10.1016/j.jocrd.2013.08.004

Lebowitz, E. R., Panza, K. E., Su, J., & Bloch, M. H. (2012). Family accommodation in obsessive-compulsive disorder. *Expert Review of Neurotherapeutics, 12*(2), 229-238. doi: 10.1586/ern.11.200

Lebowitz, E. R., Vitulano, L. A., & Omer, H. (2011). Coercive and disruptive behaviors in pediatric obsessive compulsive disorder: A qualitative analysis. *Psychiatry, 74*(4), 362-371.

Leckman, J. F., Sholomskas, D., Thompson, W. D., Belanger, A., & Weissman, M. M. (1982). Best estimate of lifetime psychiatric diagnosis: a methodological study. *Archives of General Psychiatry, 39*(8), 879-883.

Lee, L. C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: quality of life and parental concerns. *Journal of Autism and Developmental Disorders, 38*(6), 1147-1160. doi: 10.1007/s10803-007-0491-0

Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales*. Sydney: Psychology Foundation.

Maina, G., Saracco, P., & Albert, U. (2006). Family-focused treatments for obsessive-compulsive disorder. *Clinical Neuropsychiatry, 3*(6), 382-390.

Mansfield, E. R., & Helms, B. P. (1982). Detecting multicollinearity. *The American Statistician, 36*(3a), 158-160. doi: 10.1080/00031305.1982.10482818

Marien, W. E., Storch, E. A., Geffken, G. R., & Murphy, T. K. (2009). Intensive family-based cognitive-behavioral therapy for pediatric obsessive-compulsive disorder: Applications for treatment of medication partial- or nonresponders. *Cognitive and Behavioral Practice, 16*(3).

Marvardi, M., Mattioli, P., Spazzafumo, L., Mastriforti, R., Rinaldi, P., Polidori, M. C., . . . Mecocci, P. (2005). The Caregiver Burden Inventory in evaluating the burden of caregivers of elderly demented patients: Results from a multicenter study. *Aging Clinical and Experimental Research, 17*(1), 46-53.

McCleery, A., Addington, J., & Addington, D. (2007). Family assessment in early psychosis. *Psychiatry Research, 152*(2-3), 95-102. doi: 10.1016/j.psychres.2006.07.002

Menard, S. (1995). *Applied logistic regression analysis: Sage Unviersity series on quantitative applications in the social sciences*. Thousand Oaks, CA: Sage.

Mendlowicz, M. V., & Stein, M. B. (2000). Quality of life in individuals with anxiety disorders. *American Journal of Psychiatry, 157*(5), 669-682.

Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing, 32*(2), 218-223.

Nakamura, B. J., Ebesutani, C., Bernstein, A., & Chorpita, B. F. (2009). A psychometric analysis of the child behavior checklist DSM-oriented scales. *Journal of Psychopathology and Behavioral Assessment, 31*(3), 178-189.

Negm, M. G., Mahdy, R. S., Khashaba, A. M., & Abd El-Latif, R. R. (2014). Comparison of family burden, quality of life, and disability in obsessive compulsive disorder and schizophrenia in Zagazig University Hospitals. *Egyptian Journal of Psychiatry, 35*(1), 39. doi: 10.4103/1110-1105.127276

Ng, F., Trauer, T., Dodd, S., Callaly, T., Campbell, S., & Berk, M. (2007). The validity of the 21-item version of the Depression Anxiety Stress Scales as a routine clinical outcome measure. *Acta Neuropsychiatrica, 19*(5), 304-310. doi: 10.1111/j.1601-5215.2007.00217.x

Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *Gerontologist, 29*(6), 798-803.

Papastavrou, E., Tsangari, H., Karayiannis, G., Papacostas, S., Efstathiou, G., & Sourtzi, P. (2011). Caring and coping: The dementia caregivers. *Aging & Mental Health, 15*(6), 702-711. doi: 10.1080/13607863.2011.562178

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist, 30*(5), 583-594.

Peris, T. S., Bergman, R. L., Langley, A., Chang, S., McCracken, J. T., & Piacentini, J. (2008). Correlates of accommodation of pediatric obsessive-compulsive disorder: parent, child, and family characteristics. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(10), 1173-1181. doi: 10.1097/CHI.0b013e3181825a91

Phares, V., & Compas, B. E. (1992). The role of fathers in child and adolescent psychopathology: make room for daddy. *Psychological Bulletin, 111*(3), 387.

Piacentini, J., Bergman, R. L., Jacobs, C., McCracken, J. T., & Kretchman, J. (2002). Open trial of cognitive behavior therapy for childhood obsessive-compulsive disorder. *Journal of Anxiety Disorders, 16*(2), 207-219.

Piacentini, J., Peris, T. S., Bergman, R. L., Chang, S., & Jaffer, M. (2007). Functional impairment in childhood OCD: development and psychometrics properties of the Child

Obsessive-Compulsive Impact Scale-Revised (COIS-R). *Journal of Clinical Child and Adolescent Psychology, 36*(4), 645-653. doi: 10.1080/15374410701662790

Pinto, A., Van Noppen, B., & Calvocoressi, L. (2013). Development and preliminary psychometric evaluation of a self-rated version of the Family Accommodation Scale for Obsessive-Compulsive Disorder. *Journal of Obsessive-Compulsive and Related Disorders, 2*(4), 457-465. doi: 10.1016/j.jocrd.2012.06.001

Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods, 40*(3), 879-891.

Ramos-Cerqueira, A. T., Torres, A. R., Torresan, R. C., Negreiros, A. P., & Vitorino, C. N. (2008). Emotional burden in caregivers of patients with obsessive-compulsive disorder. *Depression and Anxiety, 25*(12), 1020-1027. doi: 10.1002/da.20431

Ryan, C. E., Epstein, N. B., Keitner, G. I., Miller, I. W., & Bishop, D. S. (2005). *Evaluating and Treating Families: The McMaster Approach*. London: Routledge.

Sales, E. (2003). Family burden and quality of life. *Quality of Life Research, 12 Suppl 1*, 33-41.

Saunders, J. C. (2003). Families living with severe mental illness: a literature review. *Issues in Mental Health Nursing, 24*(2), 175-198.

Scahill, L., Riddle, M. A., McSwiggin-Hardin, M., Ort, S.I., King, R.A., Goodman, W. K., . . . Leckman, J.F. (1997). Children's Yale-Brown Obsessive Compulsive Scale: reliability and validity. *Journal of the American Academy of Child & Adolescent Psychiatry, 36*(6), 9.

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA, 282*(23), 2215-2219.

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist, 35*(6), 771-791.

Settineri, S., Rizzo, A., Liotta, M., & Mento, C. (2014). Caregiver's burden and quality of life: Caring for physical and mental illness. *International Journal of Psychological Research, 7*(1), 30-39.

Siu, B. W., Lam, C. L., & Chan, W. C. (2012). Pattern and determinants of burden in Chinese families of adults with obsessive-compulsive disorder. *Journal of Anxiety Disorders, 26*(1), 252-257. doi: 10.1016/j.janxdis.2011.11.008

Skevington, S. M., Lotfy, M., O'Connell, K. A., & WHOQOL Group. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research, 13*(2), 299-310.

Spitzer, R. L., Kroenke, K., Linzer, M., Hahn, S. R., Williams, J. B., deGruy, F. V., 3rd, . . . Davies, M. (1995). Health-related quality of life in primary care patients with mental disorders. Results from the PRIME-MD 1000 Study. *JAMA, 274*(19), 1511-1517.

Steketee, G., & Van Noppen, B. (2003). Family approaches to treatment for obsessive compulsive disorder. *Revista Brasileira de Psiquiatria, 25*(1), 43-50.

Stengler-Wenzke, K., Kroll, M., Matschinger, H., & Angermeyer, M. C. (2006). Quality of life of relatives of patients with obsessive-compulsive disorder. *Comprehensive Psychiatry, 47*(6), 523-527. doi: 10.1016/j.comppsych.2006.02.002

Stewart, S. E., Hu, Y. P., Hezel, D. M., Proujansky, R., Lamstein, A., Walsh, C., . . . Pauls, D. L. (2011). Development and psychometric properties of the OCD Family Functioning (OFF) Scale. *Journal of Family Psychology, 25*(3), 434-443. doi: 10.1037/a0023735

Stewart, S. E., Yen, C. H., Stack, D. E., & Jenike, M. A. (2006). Outcome predictors for severe obsessive-compulsive patients in intensive residential treatment. *Journal of Psychiatric Research, 40*(6), 511-519. doi: 10.1016/j.jpsychires.2005.08.007

Storch, E. A., Geffken, G. R., Merlo, L. J., Jacob, M. L., Murphy, T. K., Goodman, W. K., . . . Grabill, K. (2007). Family accommodation in pediatric obsessive-compulsive disorder. *Journal of Clinical Child and Adolescent Psychology, 36*(2), 207-216. doi: 10.1080/15374410701277929

Storch, E. A., Jones, A. M., Lack, C. W., Ale, C. M., Sulkowski, M. L., Lewin, A. B., . . . Murphy, T. K. (2012). Rage attacks in pediatric obsessive-compulsive disorder: Phenomenology and clinical correlates. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(6), 582-592.

Storch, E. A., Larson, M. J., Muroff, J., Caporino, N., Geller, D., Reid, J. M., . . . Murphy, T. K. (2010). Predictors of functional impairment in pediatric obsessive-compulsive disorder. *Journal of Anxiety Disorders, 24*(2), 275-283. doi: 10.1016/j.janxdis.2009.12.004

Storch, E. A., Lehmkuhl, H., Pence, S. L., Geffken, G. R., Ricketts, E., Storch, J. F., & Murphy, T. K. (2009). Parental experiences of having a child with obsessive-compulsive disorder: Associations with clinical characteristics and caregiver adjustment. *Journal of Child and Family Studies, 18*(3), 249-258. doi: 10.1007/s10826-008-9225-y

Storch, E. A., Lewin, A. B., De Nadai, A. S., & Murphy, T. K. (2010). Defining treatment response and remission in obsessive-compulsive disorder: a signal detection analysis of the Children's Yale-Brown Obsessive Compulsive Scale. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*(7), 708-717. doi: 10.1016/j.jaac.2010.04.005

Storch, E. A., Lewin, A. B., Geffken, G. R., Morgan, J. R., & Murphy, T. K. (2010). The role of comorbid disruptive behavior in the clinical expression of pediatric obsessive-compulsive disorder. *Behaviour Research and Therapy, 48*(12), 1204-1210. doi: 10.1016/j.brat.2010.09.004

Storch, E. A., Merlo, L. J., Larson, M. J., Geffken, G. R., Lehmkuhl, H. D., Jacob, M. L., . . . Goodman, W. K. (2008). Impact of comorbidity on cognitive-behavioral therapy response in pediatric obsessive-compulsive disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(5), 583-592. doi: 10.1097/CHI.0b013e31816774b1

Storch, E. A., Milsom, V. A., Merlo, L. J., Larson, M., Geffken, G. R., Jacob, M. L., . . . Goodman, W. K. (2008). Insight in pediatric obsessive-compulsive disorder: associations with clinical presentation. *Psychiatry Research, 160*(2), 212-220. doi: 10.1016/j.psychres.2007.07.005

Storch, E. A., Murphy, T. K., Geffken, G. R., Soto, O., Sajid, M., Allen, P., . . . Goodman, W. K. (2004). Psychometric evaluation of the Children's Yale-Brown Obsessive-Compulsive Scale. *Psychiatry Research, 129*(1), 91-98. doi: 10.1016/j.psychres.2004.06.009

Storch, E. A., Rudy, B., Wu, M. S., Lewin, A. B., & Murphy, T. K. (2014). Moderators of impairment agreement among parent-child dyads in pediatric obsessive-compulsive disorder. *Journal of Psychopathology and Behavioral Assessment*. doi: 10.1007/s10862-014-9456-8

Stromberg, A., & Luttik, M. L. (2015). Burden of caring: Risks and consequences imposed on caregivers of those living and dying with advanced heart failure. *Current Opinion in Supportive and Palliative Care, 9*(1), 26-30. doi: 10.1097/spc.0000000000000111

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging, 26*(4), 429-453.

The Pediatric OCD Treatment Study (POTS) Team. (2004). Cognitive-behavior therapy, sertraline, and their combination with children and adolescents with obsessive-compulsive disorder: the Pediatric OCD Treatment Study (POTS) randomized controlled trial. *Journal of the American Medical Association, 292*(16), 1969-1976.

The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*(3), 551-558.

Thomas, J. K., Suresh Kumar, P. N., Verma, A. N., Sinha, V. K., & Andrade, C. (2004). Psychosocial dysfunction and family burden in schizophrenia and obsessive compulsive disorder. *Indian Journal of Psychiatry, 46*(3), 238-243.

Torres, A. R., Hoff, N. T., Padovani, C. R., & Ramos-Cerqueira, A. T. (2012). Dimensional analysis of burden in family caregivers of patients with obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences, 66*(5), 432-441. doi: 10.1111/j.1440-1819.2012.02365.x

Valderhaug, R., & Ivarsson, T. (2005). Functional impairment in clinical samples of Norwegian and Swedish children and adolescents with obsessive-compulsive disorder. *European Child and Adolescent Psychiatry, 14*(3), 164-173. doi: 10.1007/s00787-005-0456-9

Verma, M., & Sinha, U. K. (2013). Burden of care and stress in family members of patients suffering from obsessive compulsive disorder. *Delhi Psychiatry Journal, 16*(2), 375-379.

Vikas, A., Avasthi, A., & Sharan, P. (2011). Psychosocial impact of obsessive-compulsive disorder on patients and their caregivers: A comparative study with depressive disorder. *International Journal of Social Psychiatry, 57*(1), 45-56. doi: 10.1177/0020764009347333

Whiteside, S. P., & Jacobsen, A. B. (2010). An uncontrolled examination of a 5-day intensive treatment for pediatric OCD. *Behavior Therapy, 41*(3), 414-422. doi: http://dx.doi.org/10.1016/j.beth.2009.11.003

Wu, M. S., & Lewin, A. B. (in press). Insight in obsessive-compulsive disorder. In D. McKay, E. A. Storch & J. S. Abramowitz (Eds.), *Handbook of Obsessive-Compulsive Disorder Across the Lifespan*: Wiley.

Wu, M. S., Lewin, A. B., Murphy, T. K., Geffken, G. R., & Storch, E .A. (2014). Phenomenological considerations of family accommodation: Related clinical characteristics and family factors in pediatric OCD. *Journal of Obsessive-Compulsive and Related Disorders, 3*(3), 228-235.

Wu, M. S., Pinto, A., Horng, B., Phares, V., McGuire, J. F., Dedrick, R. F., . . . Storch, E. A. (2016). Psychometric properties of the Family Accommodation Scale for Obsessive-Compulsive Disorder – Patient Version. *Psychological Assessment, 28*(3), 251-262.

Yamazaki, S., Sokejima, S., Mizoue, T., Eboshida, A., & Fukuhara, S. (2005). Health-related quality of life of mothers of children with leukemia in Japan. *Quality of Life Research, 14*(4), 1079-1085.

Zohar, A. H. (1999). The epidemiology of obsessive-compulsive disorder in children and
adolescents. *Child and Adolescent Psychiatric Clinics of North America, 8*(3), 445-460.

APPENDIX 1

Tables

Table 1

Table of Measures Completed by the Clinician, Parent, and Child

	Clinician	Parent	Child
CY-BOCS	X		
FAS-IR	X		
CBI		X	
WHOQOL-BREF		X	
SDS (P)		X	
FAD-12		X	
CSI-16		X	
PAoC		X	
DASS21		X	
CBCL		X	
Demographics		X	
SDS (C)			X

Note. CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale; FAS-IR = Family Accommodation Scale for Obsessive-Compulsive Disorder – Interviewer Rated; CBI = Caregiver Burden Inventory; WHOQOL-BREF = World Health Organization Quality of Life – BREF; SDS-P/C = Sheehan Disability Scale – Parent/Child Report; FAD-12 = Family Assessment Device – 12 Item Version; CSI-16 = Couples Satisfaction Index – 16; PAoC = Positive Aspects of Caregiving; DASS21 = Depression Anxiety Stress Scale – Short Version; CBCL = Child Behavior Checklist.

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	-.03	-.05	.09	.05	.08
SDS-P	-.27*	-.19	-.13	.00	-.10
SDS-C	-.09	.01	.10	.13	.08
FAS	-.20	-.13	-.26*	-.11	-.01
DASS Anxiety	-.11	-.45***	-.45***	-.14	-.29*
DASS Depression	-.43***	-.58***	-.84***	-.50***	-.55***
CBCL – Int	-.15	-.20	-.18	-.10	-.22
CBCL – Ext	-.25*	-.14	-.16	-.07	-.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

Note. * $p < .05$, ** $p < .01$, *** $p < .001$; 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).

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	.15	.43***	.10	-.12	.21	.07
SDS-P	.46***	.53***	.40**	.22	.26*	.29*
SDS-C	.05	.33*	.12	-.09	-.07	.00
FAS	.49***	.67***	.34**	.18	.34**	.22
DASS Anxiety	.35**	.23	.14	.23	.43***	.08
DASS Depression	.49***	.22	.34**	.50***	.55***	.28*
CBCL – Int	.25*	.33**	.15	-.00	.20	.23
CBCL – Ext	.42***	.32***	.25*	.14	.18	.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

Note. * $p < .05$, ** $p < .01$, *** $p < .001$; 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).

Table 4

Means, Standard Deviations, Ranges, and Correlations between OCD Symptom Severity and Family Variables

	FAD	CSI-16	PAoC Self-Affirmation	PAoC Outlook on Life	PAoC Total
CY-BOCS	.06	-.08	-.09	.05	-.05
Mean	25.89	49.04	17.03	8.64	25.67
SD	8.62	21.76	5.72	3.27	7.68
Range	12 – 48	0 – 81	6 – 28	3 – 15	9 – 41

Note. * $p < .05$, ** $p < .01$, *** $p < .001$; CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale total score ($n = 71$); FAD-12 = Family Assessment Device – 12 Item Version total score ($n = 63$); CSI-16 = Couples Satisfaction Index – 16 total score ($n = 57$); PAoC = Positive Aspects of Caregiving ($n = 64$).

Table 5

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

Note. 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 6

Hierarchical Multiple Regression Analyses for Predicting Caregiver QoL and Burden beyond OCD Symptom Severity

Predictor	B	$SE(B)$	β	R^2	ΔR^2	F for ΔR^2
Predicting Caregiver QoL						
Step 1						
Constant	3.24	0.60				
CY-BOCS Total	0.00	0.02	-0.03	0.00		
Step 2						
Constant	3.84	0.55				
CY-BOCS Total	-0.01	0.02	-0.03			
CBCL Internalizing	0.01	0.01	0.07			
CBCL Externalizing	-0.03	0.02	-0.25			
DASS Anxiety	0.04	0.03	0.27			
DASS Depression	-0.06	0.02	-0.58***	0.28	0.28	5.34**
Predicting Caregiver Burden						
Step 1						
Constant	30.23	10.68				
CY-BOCS Total	0.45	0.37	0.16	0.03		
Step 2						
Constant	13.78	9.33				
CY-BOCS Total	0.59	0.32	0.21			
CBCL Internalizing	-0.21	0.21	-0.14			
CBCL Externalizing	0.71	0.23	0.41**			
DASS Anxiety	0.23	0.42	0.08			
DASS Depression	0.67	0.25	0.40**	0.39	0.36	7.91***

Note. ** $p < .01$, *** $p < .001$; CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale; DASS = Depression Anxiety Stress Scale – Short Version; CBCL = Child Behavior Checklist.