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ORIGINAL PAPER

Predictors of early adulthood quality of life in children with obsessive–compulsive disorder

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Abstract
Objectives The goal of this study was to determine childhood clinical predictors of quality of life (QoL) in early adulthood in children with obsessive–compulsive disorder (OCD).
Methods A longitudinal cohort study was conducted with 36 (out of 62 eligible) children with OCD, interviewed once at childhood baseline (mean age 12.1 ± 2.1, range 8.0–15.8), and again in early adulthood after an average follow-up interval of 9 years. QoL was measured in adulthood with the longitudinal interval follow-up evaluation range of impaired functioning tool (LIFE-RIFT).
Results Forty-two percent of children experienced a remission of OCD symptoms by early adulthood. OCD appeared to most strongly impair the interpersonal relationships and work domains of QoL. QoL and severity of OCD and anxiety symptoms were significantly associated in early adulthood. Primary hoarding symptoms in childhood predicted poor QoL in adulthood. Increased symptoms in the forbidden thoughts dimension in both childhood and adulthood were associated with improved adulthood QoL.
Conclusions Children for whom OCD symptoms remitted by adulthood showed no evidence of residual impairment in QoL, whereas children whose OCD symptoms failed to remit by adulthood showed at most mild impairment in QoL. Hoarding symptoms in childhood appear to portend not only the persistence of OCD symptoms but also poorer QoL in early adulthood.

Keywords Obsessive–compulsive disorder · Quality of life · LIFE-RIFT · Longitudinal study · Compulsive hoarding

Introduction

Obsessive–compulsive disorder (OCD) is a psychiatric illness present in 1–3% of both children and adults. OCD is characterized by obsessions—intrusive, unwanted thoughts, images, impulses, and compulsions—stereotyped mental or physical actions that typically reduce anxiety and distress caused by the obsessions [1–3]. OCD significantly diminishes quality of life (QoL) in afflicted children and adults [4, 5]. Indeed, OCD is projected by the World Health Organization to be the 10th most disabling condition in the developed world by the year 2012 [6]. OCD can impair QoL by reducing the quality of social and family relationships, reducing self-esteem, and impairing school and work functioning. Over one-third of adults with OCD are single or struggle in their relationships. Thirty percent of adults with OCD have difficulty in working and 62% report OCD-related problems at work. More than 90% of adults with OCD experience low self-esteem [7, 8]. The number of OCD symptoms correlates negatively with QoL in adults

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with OCD [9]. OCD in adults is associated with a worse QoL than other anxiety disorders, with the exception of post-traumatic stress disorder (PTSD) [8].

By contrast, QoL in pediatric-onset OCD has been sparsely studied. One report indicated that poorer QoL in children with OCD is associated with more severe OCD symptoms, the presence of comorbid internalizing and externalizing symptoms, and female gender [5]. With the introduction of evidence-based treatments for OCD, such as serotonin reuptake inhibitors and cognitive behavioral therapy, a large portion of children with OCD experiences a dramatic improvement of their symptoms [10]. A meta-analysis has shown that 40–59% of children with OCD experience a remission of OCD symptoms when followed up for at least 1 year later [11]. In this meta-analysis, the persistence of OCD symptoms was associated with earlier age of OCD onset, increased duration of illness prior to treatment, and inpatient hospitalization for OCD. Among the cohort of pediatric OCD patients included in this study, the persistence of OCD symptoms into early adulthood was associated with primary hoarding symptoms and the absence of comorbid tics [12].

During clinical assessments for childhood OCD, families are extremely concerned about prognosis. Many parents' foremost question is "What will happen to my child?" [11]. This question usually has two components: (1) "Will my child's OCD get better?" and (2) "Will my child grow up to have a fulfilling life?" Investigators have been most successful at answering the former question, i.e., (1) when combining SSRIs and CBT, there is a better than 50/50 chance that your child's OCD will remit within 3 months of treatment (compared to a less than 5% chance of remission with no treatment) [10]; (2) over the long-term, most children's symptoms stay improved and over half of children's OCD symptoms remain remitted over the long term [11]. However, we know much less about long-term QoL and how to answer questions like "Will my child have fulfilling family and social relationships as an adult?", "Will my child be successful at work?", "Will my child be happy when he grows up?"

Our study looks at adulthood outcome in terms of QoL in a cohort of children with OCD who were followed into early adulthood. Our goal was to determine childhood predictors and adulthood correlates of QoL in early adulthood in this cohort. We hypothesized that in adulthood, levels of OCD symptom severity and dimensional OCD symptom severity scores would be associated with current adulthood QoL. We also hypothesized that in children with OCD, (1) primary hoarding symptoms would predict a lower adulthood QoL and (2) that the presence of a comorbid tic disorder in childhood would predict improved QoL.

We hypothesized that primary hoarding symptoms would be associated with poor adulthood QoL because they have been previously associated with (1) the persistence of pediatric-onset OCD symptoms [12], (2) poor response to pharmacological and behavioral treatments for OCD [13, 14] and (3) increased comorbid emotional difficulties in children [15]. We hypothesized that comorbid tic symptoms would be associated with improved adulthood QoL because they have been associated previously with the remittance of pediatric-onset OCD symptoms [12]. Tics in OCD patients have been previously associated with a differential response to pharmacological interventions for OCD such as sertraline treatment and antipsychotic augmentation [16, 17].

Patients and methods

Subjects

We conducted a longitudinal follow-up study of adulthood outcomes in pediatric-onset OCD. To participate in the full study, participants were required to: (1) have an OCD diagnosis in childhood; (2) complete an MRI scan and neuropsychological testing studies before reaching the age of 16 and; (3) have reached 16 years of age or older at the time of follow-up. Exclusion criteria included head trauma resulting in loss of consciousness, an IQ lower than 80, past or ongoing substance abuse, and history of seizure. Forty-six out of 62 eligible participants agreed to follow-up interviews. One subject subsequently diagnosed with Asperger's disorder was dropped from the follow-up sample after his diagnosis was confirmed by physician's evaluation (MHB) at follow-up. Nine out of the remaining 45 subjects who participated in follow-up interview did not complete follow-up QoL ratings. These were subjects who withdrew from the follow-up interview after initially agreeing typically due to the length of time of the follow-up assessment (3 h).

Childhood baseline interview occurred at an average age of 12.1 ± 2.1 years (range 8.0–15.8). Follow-up interviews occurred at an average age of 21.1 ± 3.1 years (range 16.0–27.0). The average interval between the baseline and follow-up interviews was 9 ± 2.9 years. QoL information was not available on eight additional individuals from the original cohort. Informed consent was attained from parents and participants at the time of the childhood baseline assessment and at follow-up. Baseline demographic information on participants and non-participants in this study are given in Table 1.

Table 1 Subject demographics

Demographic	Participants	Remitted	Non-remitted	Non-participants
N	36	15	21	16
Age	12.1 ± 2.0	12.2 ± 2.2	12.1 ± 1.9	9.9 ± 1.6
Gender (% male)	78%	93%	67%	75%
OCD severity at childhood MRI	10.8 ± 7.3	8.0 ± 5.0	13.0 ± 8.3	14.2 ± 9.8
Tics	53%	31%	79%	69%
ADHD	53%	47%	57%	38%
Primary hoarding	25%	7%	38%	6%
Medication use in childhood				
SRI	94%	100%	90%	56%
Neuroleptics	50%	56%	43%	31%
Alpha-2 agonists	28%	27%	29%	6%
Medication use in adulthood				
SRI	61%	60%	62%	
Neuroleptics	14%	19%	10%	
Alpha-2 agonists	3%	0%	5%	

Baseline subject demographics and medication use comparing participants and non-participants and children whose OCD did and did not remit by adulthood. Yale-Brown Obsessive–Compulsive Score of less than 8 was our criteria for remission

Baseline assessment in childhood

Baseline assessment was conducted when children were less than 16 years of age. The procedures of our baseline assessment have been described previously in more detail [12]. A structured diagnostic interview was conducted with the Schedule for Tourette and Other Behavioral Syndromes and clinical diagnoses established by two psychiatrists utilizing a best-estimate consensus procedure following a review of all available materials [18, 19]. Diagnoses classified participants based on the presence or absence of the following conditions: chronic tic disorder (CTD), major depressive disorder (depression), oppositional defiant disorder (ODD), Tourette's syndrome (TS), comorbid anxiety disorder besides OCD (anxiety), and attention-deficit hyperactivity disorder (ADHD). Current and worst-ever severities of OCD and tic symptoms were rated using the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) and Yale Global Tic Severity Scale (YGTSS), respectively [20, 21]. Severity of comorbid depressive symptoms was measured with the Children's Depression Rating Scale (CDRS) [22]. Finally, a detailed interview concerning medication history, family history, age of onset of OCD, and tic symptoms was also conducted at baseline.

Based on data collected at childhood [baseline clinical assessment, CY-BOCS symptom checklist and symptom dimensional factor scores (see [23] for further details), individuals were classified into four mutually exclusive primary symptom dimensions (cleaning, forbidden thoughts, symmetry and hoarding) by a rater blinded to adulthood outcome. Primary symptom dimension was defined as the OCD symptoms causing the greatest distress and impairment in global functioning.

Follow-up assessment in adulthood

During the early adulthood follow-up assessment, current and worst-ever ratings of OCD and tic severity were determined using the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) and YGTSS [20, 21]. Dimensional symptoms of OCD were evaluated using the Dimensional Yale-Brown Obsessive–Compulsive Scale (DY-BOCS) [24]. The *Structured Clinical Interview for* DSM-IV *Axis I Disorder* was used to screen for comorbid psychiatric conditions. QoL was measured IN adulthood with the longitudinal interval follow-up evaluation range of impaired functioning tool (LIFE-RIFT) [25]. The LIFE-RIFT is a semi-structured, clinician-rated measure of functional impairment. The LIFE-RIFT has a total score comprised individual domain scores for the following areas of functioning: household duties, work, recreation, relationships with family, relationships with friends, schoolwork, and global life satisfaction (this item is patient-rated). Scores in each domain range from 1 to 5, with higher scores indicating worse functioning. A detailed medication, family, and medical history were taken during the follow-up interview. When possible, a family member or co-habitating adult was interviewed to augment the subjects' interviews.

Data analysis

All statistical analyses were performed in SPSS version 16.0. Persons with remitted OCD ("remitters") were compared to adults whose OCD did not remit ("non-remitters") on QoL measures using a Student's *t* test. A Y-BOCS score of <8 was chosen as our criteria for remission because the anchor point of 8 demarcates subclinical (YBOCS 0-7) from clinical OCD symptoms (YBOCS $\geq$ 8) [26]. Our a priori hypothesis was that non-remitters would have higher LIFE-RIFT scores (indicating a greater impairment in functioning) than remitters. In exploratory analyses, each of the four subdomains of the LIFE-RIFT was compared between the two groups. A statistical threshold of $P < 0.05$ was used for all *t* tests. The analysis regarding the LIFE-RIFT subdomains should be considered exploratory and used for hypothesis generating purposes only.

Linear regression was performed to determine (1) clinical characteristics in early adulthood associated with concurrent QoL and (2) childhood baseline characteristics that predict future QoL. For all linear regression analyses, the primary outcome and dependent variable was total LIFE-RIFT score. Before linear regression was performed, a histogram of LIFE-RIFT score at adulthood follow-up was inspected for normality.

For the investigation of concurrent adulthood clinical characteristics associated with QoL at the time of follow-up, gender and age at follow-up assessment were added as covariates. Our two a priori hypotheses in this analysis were that adulthood measures of OCD symptom severity and OCD symptom dimension scores on the DY-BOCS would correlate with adulthood measures of QoL. Current Y-BOCS severity was added as an additional covariate in our hypothesis testing of the correlation of OCD symptom dimension severity scores on the DY-BOCS. The dimensional severity scores from the aggression and sexual/religious dimensions of the DY-BOCS were combined a priori based on recent evidence that these two symptom clusters form a single OCD symptom dimension [27]. The statistical threshold for significance was set at $P < 0.025$ using a strict Bonferroni correction to account for our two a priori hypotheses. In exploratory analyses, we additionally conducted a forward stepwise linear regression model to determine the best-fitting model of adulthood variables associated with concurrent QoL. The criteria for entry into the model were $P < 0.05$ and exit was $P > 0.1$. The variables included in this model were current OCD severity (Y-BOCS), current depression symptom severity (Hamilton Depression Rating Scale), current anxiety symptom severity (Hamilton Anxiety Rating Scale), symptom dimension scores on the DY-BOCS, current tic symptom severity (YGTSS), number of comorbid anxiety disorders and presence of comorbid substance use disorder at follow-up. Most adulthood clinical variables with the exception of gender, presence of substance use disorder and number of anxiety disorders were highly intercorrelated. We decided to include all of them despite significant intercorrelation because we felt that they represented clinically important variables. We additionally used forward stepwise regression as our method of analysis to limit the effect of these intercorrelations on our final analysis. Specific intercorrelations between our exploratory variables are available as supplementary material upon request. Significant exploratory findings should be used only for hypothesis generation and not to provide conclusive confirmatory findings.

In assessing which baseline clinical characteristics in childhood predict QoL in early adulthood, we included as covariates age at baseline, age at follow-up and gender. Our three a priori hypotheses were that (1) presence of hoarding symptoms, (2) absence of comorbid tics and (3) childhood severity of OCD symptoms would predict QoL in adulthood. These hypotheses were suggested by their association with persistence of OCD symptoms in this same cohort. Our statistical threshold for significance was set at $P < 0.018$ using a strict Bonferroni correction to account for our three a priori hypotheses. In exploratory analyses, we additionally conducted a forward stepwise linear regression model to determine the best-fitting model of childhood variables predicting adulthood QoL. The criteria for entry into the model were $P < 0.05$ and exit was $P > 0.1$. The variables included in this model were worst-ever OCD severity, worst-ever tic severity, current depression severity (CDRS), age of onset, presence of tic symptoms, presence of ADHD, ODD, depression or anxiety disorder, factor scores on each of the four primary symptom dimensions (forbidden thoughts, symmetry, cleaning and hoarding). There were few significant correlations between childhood clinical variables with the exception of (1) tics and worst-ever YGTSS score, (2) primary hoarding symptoms and hoarding factor score and (3) comorbid ADHD and ODD diagnoses. We decided to include all of them despite significant intercorrelation because we felt that they represented clinically important variables. Intercorrelations between exploratory variables are available as supplementary material upon request. Significant exploratory findings should be used only for hypothesis generation and not to provide conclusive confirmatory findings.

Results

Subjects

Participants were 12.1 $\pm$ 2.0 years (range 8.0–15.8) at baseline childhood assessment. The follow-up assessment

in adulthood occurred after an average duration of 9.0 ± 2.0 years. The average age at early adulthood interviews was 21.1 ± 3.1 years (range 16.0–27.0). We re-interviewed 36 out of 61 eligible participants at adulthood follow-up. At the time of the adulthood follow-up assessment, OCD had remitted in 15 participants' (42%) OCD (Y-BOCS < 8); 14 (39%) had minimal OCD (YBOCS: 8–15); 5 (14%) had moderate OCD (Y-BOCS: 16–23); and 2 (6%) had severe OCD (YBOCS > 23). Table 1 describes the demographic characteristics of participants and non-participants in the current study. Medication use is also described in Table 1.

Based on data at childhood assessment, 9 participants (1 remitted, 8 non-remitted) had primary hoarding symptoms, 11 participants with primary symptoms in the forbidden thoughts dimension (5 remitted, 6 non-remitted), 10 participants with primary symptoms in the symmetry dimension (6 remitted, 4 non-remitted) and 6 participants with primary symptoms in the cleaning dimension (3 remitted, 3 non-remitted).

Remitters versus non-remitters

Remitters demonstrated significantly better QoL than non-remitters, particularly in the LIFE-RIFT domains of interpersonal relationships and work. Comparison of remitters to non-remitters on overall QoL and LIFE-RIFT domain scores is depicted in Table 2.

Clinical correlates of QoL in adulthood

In accordance with our a priori hypotheses, OCD severity in early adulthood was associated with QoL in adulthood [$\beta = 0.168$, SE $= 0.041$, $P < 0.001$; $F(3,32) = 5.4$, $P = 0.004$, $R^2 = 0.34$]. For analyses of OCD symptom dimensions (while controlling for overall OCD severity), more symptoms in the Forbidden Thoughts dimension (combined aggression, sexual, and religious items on the DY-BOCS) were associated with an improved QoL in adulthood [$\beta = -0.158$, SE $= 0.075$, $P = 0.045$; $F(4,31) = 5.3$, $P = 0.003$, $R^2 = 0.43$] for a given degree of overall OCD severity.

In our best-fitting exploratory model [$F(3,32) = 9.8$, $P < 0.001$, $R^2 = 0.53$], the overall severity of current OCD ($\beta = 0.185$, SE $= 0.050$, $P = 0.001$) and anxiety symptoms ($\beta = 0.195$, SE $= 0.074$, $P = 0.014$) as well as the severity of forbidden thoughts symptoms on the DY-BOCS ($\beta = -0.268$, SE $= 0.080$, $P = 0.003$) were included in the model. Decreased OCD and anxiety symptom severity and increased symptomatology in the forbidden thoughts dimension were associated with improved QoL.

Childhood predictors of QoL in adulthood

In accordance with our a priori hypotheses, primary hoarding OCD symptoms in childhood [$\beta = 2.370$, SE $= 0.884$, $P = 0.01$; $F(4,31) = 2.8$, $P = 0.04$, $R^2 = 0.27$] predicted poorer QoL in early adulthood. By contrast, OCD severity in childhood [$\beta = 0.015$, SE $= 0.0.059$, $P = 0.80$; $F(4,31) = 1.2$, $P =$ NS) and the presence of a comorbid tic disorder in childhood [$\beta = 0.140$, SE $= 0.808$, $P = 0.86$; $F(4,31) = 1.0$, $P =$ NS] were not associated with QoL in adulthood.

In our best-fitting exploratory model [$F(2,33) = 6.8$, $P < 0.01$, $R^2 = 0.38$), only the presence of primary hoarding symptoms in childhood ($\beta = 3.331$, SE $= 1.048$, $P = 0.004$) and factor score on the forbidden thoughts dimension ($\beta = -2.996$, SE $= 1.159$, $P = 0.02$) were included in the model. The presence of hoarding symptoms and lower scores on the forbidden thoughts dimension were associated with poor adulthood QoL.

Table 2 Comparing remitters versus non-remitters on the LIFE-RIFT and its domains

	Remitters ($N = 21$)	Non-remitters ($N = 16$)
LIFE-RIFT*	6.5 ± 1.6	8.8 ± 3.5
Work**	1.4 ± 0.7	2.4 ± 1.6
Interpersonal relations*	1.9 ± 0.7	2.6 ± 1.3
Satisfaction	1.7 ± 0.6	2.1 ± 1.0
Recreation	1.5 ± 0.5	1.7 ± 1.0

* $P < 0.05$; ** $P < 0.01$; higher scores on the LIFE-RIFT indicate worse functioning

Discussion

Obsessive–compulsive disorder remitted in 42% of the children who were followed into their early adulthood. An even greater percentage (57%) showed no evidence of impairment in QoL in adulthood. The severity of OCD symptoms in adulthood correlated strongly with overall QoL. Those children whose OCD symptoms remitted by adulthood showed no evidence of residual impairment in QoL. OCD remitters had average LIFE-RIFT domain scores of less than 2 in all domains (interpersonal relationships, work, satisfaction and recreation) indicating no evidence of impairment. More than half (57%) of non-remitters had some evidence of impairment in one or more of the LIFE-RIFT domains (score greater than or equal to 2) compared with 25% of remitters. Non-remitters had a mean LIFE-RIFT score of 8.8, indicating mild impairment in QoL similar to or slightly less impaired than previous cohorts of adults who recently recovered from depression

or anxiety disorders [25]. The QoL ratings in our non-remitted children show much less impairment compared to previous adult samples with other active psychiatric illnesses [25]. This result is important but not surprising since few individuals were still receiving active psychiatric treatment. These findings should provide hope to families of children with OCD because they suggest fairly good adulthood QoL even if OCD symptoms do not remit completely. Non-remitters were most impaired in interpersonal relationships and work functioning, although the average impairment in these domains was still in the mild range.

Consistent with our a priori hypotheses, primary hoarding OCD symptoms in childhood predicted poorer QoL in adulthood. Past studies have demonstrated worse treatment response with cognitive-behavioral therapy and pharmacotherapy in OCD patients with hoarding symptoms [12, 13, 28–34]. Previous analysis in this cohort has also demonstrated that primary hoarding symptoms in childhood were associated with a persistence of OCD symptoms into adulthood [12]. Our cohort of children was unusual in having a high proportion of subjects with primary hoarding symptoms (24%) compared to other childhood OCD studies [15, 35–37]. This high proportion of hoarding subjects gave us increased power to find clinical differences in subjects with primary hoarding symptoms.

In both child and adults increased symptomatology in the forbidden thoughts dimension was associated with improved adulthood QoL. The forbidden thoughts dimension includes obsessions involving sexual and religious themes as well as obsessions involving fear of harm coming to self or others and violent and horrific images [27]. Certain checking compulsions are also often associated with the forbidden thoughts dimension [27]. Consistent with this finding, previous research has associated these symptoms with improved long-term outcome in adults with OCD [38]. Additionally, some studies have suggested that individuals with symptoms in this dimension may be more responsive to SRI pharmacotherapy [39, 40].

By contrast, no other childhood clinical characteristics predicted QoL in adulthood. Thus, childhood comorbid illnesses such as tic disorders, ADHD, depression and other anxiety disorders had no significant value for predicting QoL in early adulthood.

In light of these findings, it is important to take note of our study's limitations. First, QoL is a subjective measure that is intrinsically difficult to quantify and compare among individuals. Second, the LIFE-RIFT was only administered during the assessment in adulthood and analyzed in the absence of LIFE-RIFT data on healthy controls. Third, our sample represents a clinically referred population who were likely more severely ill but also more expertly treated than pediatric OCD patients in the general population. These factors make our results generalizable to patients in OCD specialty clinics, but less generalizable to community samples. Fourth, average LIFE-RIFT scores indicated low levels of impairment for both remitters and non-remitters. These low scores limited our statistical power to detect childhood predictors and adulthood correlates of QoL. Finally, the participants in our cohort commonly received medications and/or behavioral therapy for OCD throughout the study interval; our study therefore reports on the clinical course of OCD with treatment rather than on the natural history of the untreated disorder.

Our cohort of children with OCD followed to early adulthood showed modest impairment of QoL on average. QoL in adulthood was correlated strongly with residual OCD symptom severity in adulthood, but not with OCD symptom severity in childhood. Primary hoarding symptoms in childhood predicted persistence of OCD symptoms in adulthood and poorer QoL in adulthood in our study. Continued research into developing better behavioral and pharmacological treatment for individuals with compulsive hoarding symptoms is needed, as are controlled, longitudinal studies examining QoL in pediatric OCD.

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