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ORIGINAL CONTRIBUTION

A solid majority remit following evidence-based OCD treatments: a 3-year naturalistic outcome study in pediatric OCD

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Abstract

This study reports follow-up 2 and 3 years after the initial assessment of a sample of youth with a primary diagnosis of OCD. Participants were 109 children and adolescents, aged 5–17 years, recruited from a specialized, outpatient OCD clinic in Sweden. Patients were treated with cognitive behavioral therapy (CBT), augmented when indicated by selective serotonin reuptake inhibitor (SSRI). In cases where SSRIs were insufficient, augmentation with a second-generation antipsychotic (SGA) was applied. Participants were assessed with the Children's Yale–Brown Obsessive–Compulsive Scale (CY-BOCS), Children's OCD Impact Scale (COIS), and Children's Depressive Inventory (CDI) at follow-ups 2 and 3 years after baseline assessment. Treatment response was defined as CY-BOCS total score ≤ 15, and remission was defined as CY-BOCS total score ≤ 10. Analyzing the outcomes with linear mixed-effects models (LME) showed a decrease in OCD symptom load from 23 to 6.9 at the 3-year follow-up. Moreover, two of three (66.1%) participants were in remission, and another 19.2% had responded to treatment at the 3-year follow-up. Thus, 85.3% of participants responded to treatment. Moreover, during the follow-up period, participants' psychosocial functioning had significantly improved, and depressive symptoms had significantly decreased. The results suggest that evidence-based treatment for pediatric OCD, following expert consensus guidelines, has long-term positive effects for most children and adolescents diagnosed with OCD. The results also indicate that improvements are maintained over a 3-year period, at least, and that improvement is also found with regard to psychosocial functioning and depressive symptoms.

Keywords Obsessive–compulsive disorder · Long term · Follow-up · Pediatric · Cognitive behavioral therapy · Serotonin uptake inhibitors · Treatment outcome

Introduction

Obsessive–compulsive disorder (OCD), characterized by the presence of obsessions and compulsions, affects approximately 0.25–2.00% of children and adolescents [1–3]. Studies in adults indicate that OCD is a chronic, lifelong disorder, with high risk of relapse after treatment [4, 5]. Implementation of evidence-based treatments and evaluation of the effect of treatment is particularly important for pediatric OCD considering the high risk of chronic illness and relapses [6, 7]. OCD symptoms may severely impact the life of young people, shown to cause suffering and reduce psychosocial functioning at home, among peers, and in school. Moreover, children and adolescents with OCD experience poor quality of life; their everyday lives may become increasingly stressful due to difficulties with concentration, sleep problems, and the development of fatigue [8–11].

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Perez-Vigil et al. found, in a register-based study with sibling controls, that OCD, particularly with early age onset, is associated with strong decreases in educational attainment [12]. Furthermore, OCD in youth is often associated with other psychiatric disorders, with reported rates of co-morbidity from 50 to 80% [13–15].

The first-line treatments for pediatric OCD are cognitive behavioral therapy (CBT) and pharmacotherapy with selective serotonin reuptake inhibitors (SSRI) [16–21]. CBT is the first choice of treatment for mild to moderate pediatric OCD, with some authorities recommending combination treatment (CBT + SSRI) for moderate to severe OCD [18]. In a recent meta-analysis, Ivarsson et al. [20] found no support for starting with combined treatment for moderate to severe OCD. Based on existing evidence, pharmacotherapy with SSRI should be used when OCD symptoms increase excessively during CBT, or if the young person is unable to participate or rejects participation in CBT treatment [18, 20–22].

Little is known about the long-term course and treatment outcome for children with OCD and other psychiatric disorders. Reviewing follow-up studies of pediatric OCD, Stewart et al. [6] found that few used a prospective design, and few had repeated observations. The various durations of follow-up make it difficult to compare and interpret the results of different studies, as OCD follows a waxing and waning course. Moreover, some patients received other treatments during follow-up periods, the quality and extent of which were not controlled regarding the long-term outcome of treatment.

Efficacy studies are often conducted in university clinics with highly trained therapists, and the generalizability of the results to more typical care settings may be limited [23]. There is a need for further, naturalistic studies in routine psychiatric settings to complement these efficacy studies with more rigorous methodology [24]. However, naturalistic, long-term outcome studies of cohorts with pediatric OCD are rare [7, 25, 26], and published studies have several methodological shortcomings. Several factors may have confounded the results of these studies, among them the following foremost limitations: (1) the lack of a structured diagnostic procedure at baseline, (2) the use of self-assessments alone to measure the severity of OCD after treatment or at follow-up, and (3) the high rates of dropout from follow-up assessments. Furthermore, comparing the results from these studies is difficult due to large differences in the follow-up period after treatment—ranging from 1 to 11 years—that cover a considerable developmental period from preadolescence to adulthood (11–28 years of age) [7, 26]. Finally, treatments during the follow-up period have been poorly described [26].

The overall aim of the present study is to increase knowledge of the long-term effects of evidence-based treatment of pediatric OCD using a naturalistic design. The present prospective, long-term study includes a large cohort of children and adolescents (5–17 years old) diagnosed with OCD in whom clinical symptoms and demographic data were systematically assessed at baseline. Moreover, the patients were assessed repeatedly over a 3-year period, using semi-structured interviews in addition to reliable and validated rating scales. To our knowledge, the present study includes one of the largest cohorts of pediatric OCD that has been systematically studied over a 3-year, long-term basis and for which treatment is known and described.

Aim

The aims of the present study were: (1) to examine the clinical features and long-term naturalistic course of treatment in a cohort of young patients with OCD; (2) to examine the remission, defined as total score of 0–10 on the Children's Yale–Brown Obsessive–Compulsive Scale (CY-BOCS), response to treatment, defined as total CY-BOCS score 0–15, and functional impairment at the 2- and 3-year follow-up following the first assessment; and (3) to examine changes in depressive symptoms over time.

Methods

Subjects

A total of 109 children and adolescents (5–17 years old) diagnosed with OCD were involved in the present study. Participants were assessed and treated at a specialized pediatric OCD clinic for outpatients at the Sahlgrenska University Hospital in Gothenburg, Sweden. The study sample ($n = 109$) comprised 61 girls and 48 boys of mean age 12.9 years, including 40% younger than 12 years (22 girls and 22 boys). Only one child was younger than 7 years, and 60% were adolescents (39 girls and 26 boys). For a more detailed description of the sample characteristics and methods, see [27]. Figure 1 presents a flowchart of the study.

The severity of OCD symptoms at baseline in the sample was mostly moderate (45.0%) to severe (42.2%), as defined by CY-BOCS total score with the following criteria: mild OCD (score 11–15), moderate OCD (16–25), and severe OCD (26–40). During the 1st year, nearly all patients (95.4%) received CBT treatment and 54.1% had received SSRI treatment, but only 4.6% had been treated exclusively with SSRI. At the 1-year follow-up, 67.0% had responded to treatment and psychosocial functioning had significantly improved, as described in our previous paper [27].

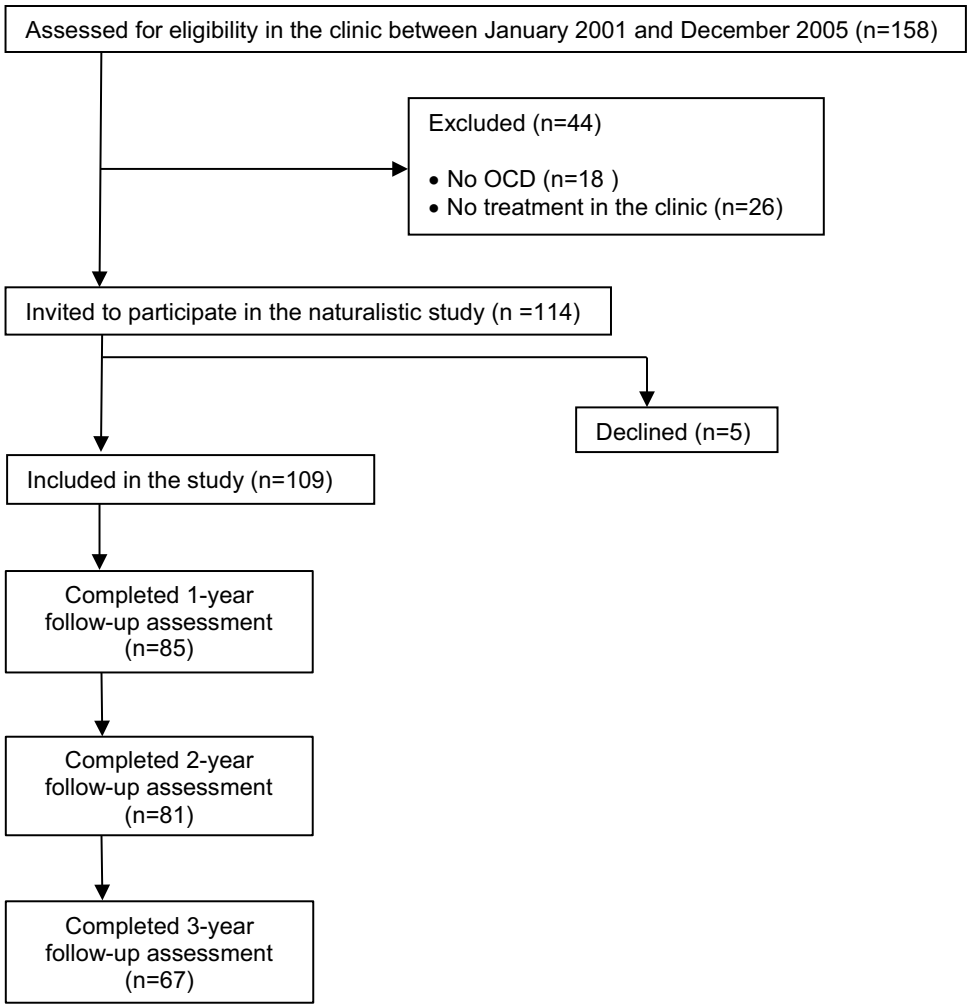

Fig. 1 Flowchart of the study

Procedures and treatment

The study was approved by the internal review board (IRB) at the University of Gothenburg (Dnr Ö 373-02). The children or adolescents and parents provided written consent before enrollment. A standardized diagnostic assessment administered at baseline comprised semi-structured clinical interviews and self- and parent-reported questionnaires. A child psychiatrist administered a diagnostic interview at baseline. All other pre-treatment assessments were administrated by therapists, who rated the severity of OCD symptoms and global impression of illness. The diagnostic workup also included self- and parent-rated scales for functional impairment from the OCD symptoms, depression, and anxiety.

The clinical long-term follow-up interviews were standardized and conducted using a "fixed window" follow-up scheme 2 and 3 years after baseline assessment. An independent evaluator at the clinic—that is, a therapist who was not involved in the patient's treatment—performed follow-up assessments, administering interviews and questionnaires.

Instruments

Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime version (K-SADS-PL) [28]: K-SADS-PL is a commonly used semi-structured interview for diagnosing psychiatric disorders according to DSM-IV criteria [28]. It assesses both present and past episodes of psychopathology through separate interviews of both the child and the parents. The evaluation may also include additional sources (e.g., medical records, school reports). The classification of symptoms uses several levels of diagnostic certainty (not present, possible, in remission, and certain). However, in the present study, OCD and comorbid diagnoses were based only on symptoms that were classified as certain. The Swedish version of K-SADS-PL was used [29]; this version was validated in a Swedish psychiatric outpatient sample [30] and has shown excellent interrater reliability and convergent and divergent validity in the Nordic countries [31].

Children's Yale–Brown Obsessive–Compulsive Scale (CY-BOCS) is a clinician-rated, semi-structured

interview that assesses the presence and severity of OCD symptoms. CY-BOCS is the most commonly used outcome measure in treatment studies on OCD in children and adolescents [32]. CY-BOCS has been found to have good psychometric properties [33–35]. CY-BOCS includes separate checklists of compulsive and obsessive symptoms that the patient and the parent endorse as present or not present. The scales measure the severity of the OCD symptoms separately for obsessions and compulsions (range 0–20), adding up to a total score (range 0–40). Subscales of insight, avoidance, indecisiveness, pathological responsibility, slowness, and pathological doubt can also be scored (range 0 to 4). This study used a Swedish version of the instrument [36].

Clinical Global Impression (CGI) is a clinician-rated global assessment of the severity of a patient´s global symptoms (in this study, OCD symptoms), using a Likert-type scale ranging from 1 (no illness) to 7 (serious illness) [37].

Children's OCD Impact Scale (COIS) is a 58-item questionnaire on which children or youth and parents separately rate the psychosocial impairment caused by OCD with regard to school, social settings, and the home situation [38]. COIS covers situations where impairment from OCD is common, generating subscales and a total score. Every item is rated using a Likert-type scale ranging from 0 to 3 (0 = not at all, 1 = only a little, 2 = pretty much, 3 = a lot). Both parent and child versions of the COIS have demonstrated good internal consistency, as well as construct and convergent validity [8]. A Swedish version of COIS was used in this study [9].

Children's Depression Inventory (CDI) is a self-reported scale of depressive symptoms in children and adolescents aged 7–17 years. CDI has 29 items and uses a three-point (0 = not present, 1 = present/mild, 2 = present/obvious) Likert-type scale [39, 40]. A Swedish version of CDI was used [41].

Treatment

Treatments were based on the expert consensus guidelines for evidence-based treatment [42, 43], personalized to each patient according to his or her age and developmental maturity. The main components of CBT were psychoeducation, exposure with response prevention, and relapse prevention. Drug treatment with SSRI was used when CBT response was insufficient or if the OCD disorder was considered severe, according to expert consensus guidelines [42]. In cases where SSRIs were insufficient, treatment was augmented with a second-generation antipsychotic (SGA). For a more detailed description of the treatment, see Melin et al. [27].

Statistics

Statistical analyses were performed using IBM SPSS 22. The total sample of 109 participants was included in the analyses. Primary outcome was change in CY-BOCS total score, with total scores of COIS (both child and parent ratings) and CDI as secondary outcomes. The scalar total scores of the treatment outcome measures (CY-BOCS, COIS-C/P, and CDI) were analyzed with a linear mixed-effects model (LME) [44, 45]. Fixed effects were time (baseline; 6 months; 1, 2, and 3 years). Random effects in the models included intercept and linear slope. Since LME can properly and robustly handle missing data, in the case of "missing at random" data, no multiple imputations were required. The Pearson Chi square exact test was used to analyze dichotomous values. To analyze categorical outcome data, multiple imputations were used to replace missing values. This imputation model included all baseline demographics and outcome measures, and a total of 20 multiple imputations were generated [46, 47]. Outcomes reported were calculated using Rubin's rules for combining the results of the 20 identical analyses [48].

Missing data from the 2- and 3-year follow-ups were analyzed for randomness using ANOVA. Participants with missing and non-missing data were compared by baseline CY-BOCS severity score, gender, age, age of OCD onset, and total CY-BOCS scores at 6 months, 1-, and 2-year follow-up (the latter only for analysis of 3-year follow-up). None of these comparisons identified significant differences. Consequently, the subsequent analyses assume that data were missing at random.

Results

Long-term naturalistic course of OCD treatment

At the 3-year follow-up, patients had received an average of 22 (SD = 19.1, median = 16) CBT sessions. A substantial minority of patients (37.6%) had received 25 or more CBT sessions (over 1–3 periods of treatment). Most patients (65%) had one period of treatment, with an average of 16 (SD = 15.9) CBT sessions, although more than a third (35%) had two or three periods of treatment. Sixty-six percent of the patients had completed CBT treatment by the 2-year follow-up. At the 3-year assessment, 10% of patients had an active, ongoing period of CBT, and almost a third (32%) were on continued SSRI medication. Nine patients received no CBT and were treated with SSRI only, either by their own choice or because their family situation made it impossible to administer CBT. A small number of patients ($n = 10$, 9.2%) received augmented treatment combining SSRI and SGA. Eight patients were admitted to the hospital during the 1st year after the baseline assessment, and three other

patients received inpatient treatment during follow-up (Table 1).

Outcome at long-term follow-up

Most participants were assessed at the 2-year (74.3%) and 3-year (61.5%) follow-ups. A mixed effects model of total CY-BOCS score (the primary outcome measure) showed significant reduction across time [F(4, 329.743) = 101.439, $p < 0.001$]. The estimated mean CY-BOCS total scores were 23.0 at baseline (95% CI 21.8–24.2), 9.3 at the 2-year follow-up (95% CI 7.6–11.0), and 6.9 at the 3-year follow-up (95% 5.2–8.7). Pairwise comparisons across assessment points showed significant differences from baseline to the 2-year follow-up ($p < 0.001$), as well as from baseline to the 3-year follow-up ($p < 0.001$) (Fig. 2).

The mean reduction in CY-BOCS total score from baseline to the 3-year follow-up was 64.0% (SD = 32.9). At the 3-year follow-up, 78% of patients had a 35% or greater reduction in CY-BOCS total score of 35%. Response following treatment was defined with respect to the CY-BOCS

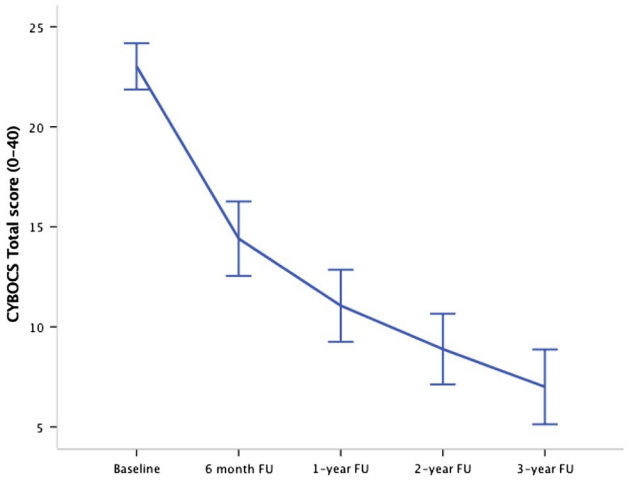

Fig. 2 Estimated Children's Yale–Brown Obsessive–Compulsive Scale (CY-BOCS) total scores from baseline to the 3-year follow-up, with 95% CI

Table 1 Comparison of demographic and clinical characteristics of patients in different groups of treatment: CBT, SSRI and CBT + SSR

Characteristics	CBT ($n = 42$)	SSRI ($n = 9$)	CBT and SSRI ($n = 58$)	p	Total ($n = 109$)
Males, [no. (%)]	18 (42.9)	3 (33.3)	27 (46.6)	n.s[a]	48 (44.0)
Age, [mean (SD) in year]	11.6 (2.3)	13.3 (3.6)	13.7 (2.2)	n.s[b]	12.9 (2.6)
Age at onset, [mean (SD) in year]	9.3 (2.8)	8.6 (3.8)	10.5 (2.8)	n.s[b]	9.9 (2.9)
CY-BOCS, total score [mean (SD)]					
Baseline	20.5 (5.5)	24.7 (6.7)	24.6 (5.9)	0.003[b]	23.0 (6.1)
1-year follow-up	8.6 (7.1)	10.8 (10.8)	12.8 (8.6)	n.s[b]	11.1 (8.3)
2-year follow-up	6.1 (6.5)	4.4 (8.7)	11.17 (8.2)	0.010[b]	8.9 (8.0)
3-year follow-up	4.1 (6.8)	0.8 (1.5)	9.4 (7.7)	0.005[b]	6.9 (7.7)
COIS-C, total score [mean (SD)]					
Baseline	27.2 (22.1)	48.3 (28.9)	50.6 (31.8)	0.002[b]	41.9 (30.3)
1-year follow-up	13.5 (18.2)	18.4 (10.6)	23.2 (26.0)	n.s[b]	19.1 (22.7)
2-year follow-up	11.0 (16.9)	4.0 (5.7)	13.3 (14.8)	n.s[b]	11.8 (15.3)
3-year follow-up	11.45 (21.4)	4.2 (6.6)	13.3 (14.8)	n.s[b]	14.2 (22.9)
COIS-P, total score [mean (SD)]					
Baseline	39.8 (28.2)	71.9 (35.7)	63.0 (32.5)	0.001[b]	55.0 (32.5)
1-year follow-up	22.0 (26.2)	37.2 (22.8)	33.7 (31.8)	n.s[b]	29.3 (29.5)
2-year follow-up	18.6 (23.0)	12.0 (9.1)	21.55 (23.5)	n.s[b]	19.9 (22.6)
3-year follow-up	12.6 (19.3)	4.3 (3.2)	21.3 (25.6)	n.s[b]	17.3 (23.2)
CDI, total score [mean (SD)]					
Baseline	8.2 (6.0)	16.2 (4.9)	13.7 (10.2)	0.023[b]	11.8 (9.0)
1-year follow-up	5.5 (6.0)	11.6 (11.6)	7.6 (6.59)	n.s[b]	7.0 (6.8)
2-year follow-up	5.2 (6.0)	5.0 (1.2)	8.3 (7.7)	n.s[b]	7.1 (7.0)
3-year follow-up	5.2 (3.5)	4.5 (4.7)	8.5 (8.0)	n.s[b]	7.2 (6.9)
Inpatients, no. (%)	0	0	11	0.029[b]	11 (10.1)
SGA, no. (%)	0	0	10	0.021[b]	10 (9.2)

[a]Pearson Chi square of groups of different groups of treatment

[b]One-way analysis of variance of different groups of treatment

total score as: free from OCD (score 0), clinical remission (scores 1–10), responders to treatment (scores 11–15), and non-responders (scores > 15). Using these criteria, nearly two of three patients (66.1%) were in remission, of which 24.8% were free from OCD, 41.3% in clinical remission, and an additional one of five, roughly, (19.2%) had responded to treatment. Thus, in total, almost nine out of ten (85.3%) participants responded to treatment. Of those with mild OCD at baseline, 92.9% responded (14.3% free from OCD, 57.1% in clinical remission, and 21.4% responded to treatment). However, there was no significant difference in remission status between those with mild OCD and those with moderate to severe OCD at baseline (Pearson Chi square test, $p = 0.50$). Approximately, 15% of patients did not respond and still had moderate (13.8%) to severe OCD (0.9%) at the 3-year follow-up. Figure 3 illustrates the severity of OCD symptoms at baseline and at the 2- and 3-year follow-ups (Fig. 3).

Impairment from OCD, as measured by COIS-C/P, reduced during the follow-up period. Using an LME model, the COIS child total score significantly reduced over time [$F(4, 67.586) = 19.419$, $p < 0.001$]. The estimated COIS-C total score was 41.3 (95% CI 35.0–47.6) at baseline, with a score of 13.2 (95% CI 9.5–16.9) at the 2-year follow-up and 14.4 (95% CI 9.4–19.5) at the 3-year follow-up. Pairwise comparisons across assessment points showed significant differences from baseline to the 2-year follow-up and from baseline to the 3-year follow-up ($p < 0.001$), but no reduction from the 2- to 3-year follow-up.

Also reduced were parental ratings of impairment due to patients' OCD. The linear mixed-effects model of total COIS-P score showed a significant reduction over time [$F(4, 81.447) = 26.382$, $p < 0.001$). The estimated COIS-P score at baseline was 54.4 (95% CI 47.7–60.5). COIS-P had decreased at the 2-year follow-up to 20.7 (95% CI 15.9–25.6) and to 16.6 (95% CI 11.4–21.8) at the 3-year follow-up. Pairwise comparisons across assessment points showed significant differences from baseline to the 2-year and 3-year follow-ups ($p < 0.001$).

Self-reported symptoms of depression, as assessed by the CDI, decreased over time. A linear mixed-effects model of the total CDI score revealed a significant effect over time [$F(4, 57.160) = 6.571$, $p < 0.001$]. The estimated CDI score at baseline was 11.8 (95% CI 9.9–13.7), estimated as 7.7 (95% CI 6.1–9.2) at the 2-year assessment and 7.6 (95% CI 5.8–9.3) at the 3-year follow-up.

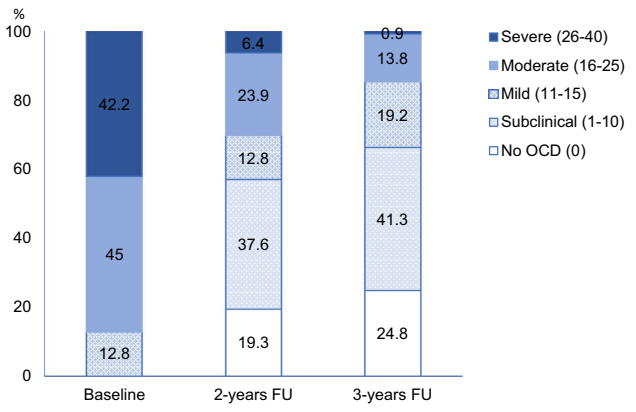

Fig. 3 Severity of OCD symptoms measured by the Children's Yale–Brown Obsessive–Compulsive Scale at baseline and at the 2- and 3-year follow-ups

Discussion

To our knowledge, the present study is one of the largest prospective studies of pediatric OCD that has systematically evaluated long-term outcomes at several points of time and that has provided a description of treatment status during the follow-up period. The current study evaluates the naturalistic course of pediatric OCD treated with CBT and/or pharmacological treatment. The results indicate that the improvements achieved after 1 year [27] were maintained during the 3-year follow-up period, although most improvement in this sample occurred during the 1st year after baseline assessment (see data in [27]). Total CY-BOCS score at long-term follow-up showed a decrease in OCD symptoms during the follow-up period, with the CY-BOCS total score falling on average from 11.2 to 6.9.

We found that 85.3% of participants ($n = 109$) who were assessed and treated at a specialist clinic for pediatric OCD in Sweden either responded to treatment or were in remission at the 3-year follow-up assessment. As the present study applied few exclusion criteria, we believe that these results showing that most youths responded well to treatment are representative. However, a minority of youths (13.8%) had moderate OCD at the 3-year follow-up; only one (0.9%) had severe OCD. Previous follow-up studies have shown much lower rates of remission (53%) [49] and response rates (67%) [25, 49]. This could be explained by the low age of patients at our follow-up, as a previous study has demonstrated higher rates of remission among youths versus adults with OCD [49]. We do not know if these favorable outcomes will persist into adulthood in our cohort. Furthermore, about one-third of youths with OCD were still receiving treatment at the 3-year follow-up, typically with SSRI medication (32%). Only four youths (3.7%) were receiving CBT at the 3-year follow-up, while two were receiving a combination of CBT and SSRI. Relapse following end of treatment could negatively affect the response and remission rates described here, but rates of ongoing treatment in the described cohort were lower than those found by a previous study of OCD [49].

OCD has been established to take an episodic or more waxing and waning course, with high risk of chronic

symptoms or disease [7]. A study of adults with OCD showed that those treated with medication alone had higher rates of relapse after discontinuing medication, although the risk of relapse decreased if the patients also received CBT [50]. We have no data on relapse rates in our sample.

OCD is often associated with the impairment of psychosocial functional and quality of life [8, 9]. Most participants in this study had little remaining impairment from OCD at the 3-year follow-up. Furthermore, even those youths with moderate or severe OCD at the 3-year follow-up showed improved psychosocial functioning.

Few youths had CDI scores indicating moderate to severe depression at baseline, and even fewer showed elevated CDI levels at follow-up. This may indicate that their reported depressive symptoms at baseline were related to the OCD, and not their psychosocial situation.

A main limitation of the present study is that we did not include a semi-structured diagnostic instrument at follow-up. However, the symptoms and severity of OCD were assessed with CY-BOCS by a clinical interview with youths and their parents, administered by an independent assessor. A second limitation is that not all youths or parents participated in all assessment points throughout the follow-up period (e.g., 6-month, 1-, 2-, and 3-year assessments). However, 74% or more (74.3–78%) participated in the first three assessments, and 61.5% completed their 3-year assessments. Analysis of this attrition, performed due to the possibility of selection bias, showed no difference in severity of illness between respondents and non-respondents to the follow-up assessments.

Because this is a naturalistic study, the lack of a control group means that we do not know to what extent the observed improvements resulted from spontaneous recovery and not our treatment. However, given the results of previous long-term outcome studies, it seems unlikely that the long-term improvements described here can be attributed exclusively to spontaneous recovery. Furthermore, in terms of clinical interpretation, the results suggest that it is important to monitor patient symptoms and offer additional treatment with CBT and/or SSRI as needed.

The strengths of the present study are a well-described sample and prospective longitudinal design with repeated assessment points over the follow-up period. These repeated assessment points and the few exclusion criteria strengthen the results' generalizability to more typical treatment settings.

In conclusion, the present study shows that evidence-based treatment for pediatric OCD following expert consensus guidelines (that is, CBT and SSRI when indicated) has a long-term, positive effect for most children and adolescents with diagnosed OCD. The findings indicate that improvements are maintained over at least a 3-year period and that improvements are also found in psychosocial functioning and depressive symptoms.

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Compliance with ethical standards

Conflicts of interest All authors declare that they have no conflicts of interest.

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