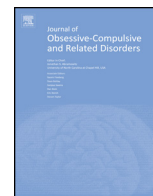




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## Clinical Report

## Phenomenology and treatment outcomes in children and adolescents from ethnic minorities with obsessive-compulsive disorder

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## ABSTRACT

Despite a similar prevalence of Obsessive-Compulsive Disorder (OCD) across ethnic groups, ethnic minorities with the disorder are under-represented in clinical services and in clinical trials. Therefore, it is uncertain whether empirically validated treatments are effective for these minority groups. We assessed whether the clinical presentation and response to multimodal treatment differed in White and non-White youths with OCD. Participants were 204 patients assessed and treated at a national specialist pediatric OCD clinic. White ( $N=169$ ) and non-White ( $N=35$ ) children and adolescents were compared on socio-demographic and clinical characteristics at baseline. OCD severity measures were administered before and after protocol-driven cognitive-behavior therapy with or without concomitant SRI medication. Mixed model analyses of covariance compared treatment outcomes in both groups. The clinical presentation was remarkably similar in White and non-White patients. Both groups received a similar number of CBT sessions and similar proportions were on concomitant SRI medication. Both groups improved similarly with treatment and similar proportions were classed as responders and remitters. Youths from ethnic minorities with OCD are indistinguishable from their White counterparts in nearly every respect and seem to respond equally well to evidence-based treatment. Efforts should be made to ensure that patients from ethnic minorities have access to treatment.

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## 1. Introduction

Obsessive-compulsive disorder (OCD) is a relatively common psychiatric disorder, with a lifetime prevalence rate of 2.3% and a 12-month prevalence rate of 1.2% in adults (Ruscio, Stein, Chiu, & Kessler, 2010). While the prevalence in very young children is lower (Heyman et al., 2001), it approaches adult levels towards the end of adolescence (Valleni-Basile et al., 1994; Zohar, 1999). Prevalence rates appear to be roughly consistent in most parts of the World where prevalence studies have been conducted (American Psychiatric Association, 2013; Fontanelle, Mendlowicz, & Versiani, 2006). The Ethnic Minority Psychiatric Illness Rates in the Community (EMPIRIC) study, carried out in the UK, examined the prevalence of mental disorders across adult British White, Black Caribbean, Indian,

Pakistani, Bangladeshi, and Irish ethnic groups. A similar point prevalence of OCD of around 1% was found across all ethnicities, although it appeared slightly more elevated among Indian women and Pakistani men (Sproston & Nazroo, 2002). Heyman et al. (2001) conducted a nationwide epidemiological survey to establish the prevalence of OCD in young people aged 5–15 in the UK and reported a significantly greater proportion of children from ethnic minorities amongst the OCD cases (24%) compared with healthy controls (8.8%) and psychiatric controls (7.4%). In the United States, Himle et al. (2008) carried out a comprehensive examination of OCD among African Americans and Black Caribbeans and found a similar prevalence of lifetime OCD in both groups. The combined prevalence for the two groups was similar to the rates of OCD found in the National Comorbidity Survey Replication (Kessler et al., 2005). Therefore, at least within western countries, there is an evidence that OCD is as prevalent – if not more – among individuals from ethnic minorities as it is in Whites.

Despite comparable prevalence rates, recent evidence shows profound ethnic inequalities in the use of services among patients

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with OCD. Fernández de la Cruz et al. (2014) showed that ethnic minorities with OCD were severely under-represented in secondary and tertiary clinical services within a large mental health trust in South London, relative to the ethnic composition of the corresponding catchment area. Moreover, the magnitude of these observed inequalities was significantly more pronounced in OCD than in depression (Fernández de la Cruz et al., 2014). OCD patients from ethnic minorities are also under-represented in clinical trials. Williams, Powers, Yun, and Foa (2010) reviewed 21 randomized controlled trials of OCD conducted in North America and found that non-Whites were seriously under-represented in such studies (91% of the participants were Caucasian). This raises the question whether evidence-based treatments are also effective for ethnic minorities with the disorder (Williams et al., 2010). To date, very few studies have looked at treatment outcomes in ethnic minorities, and these have mainly been focused on Black American populations (Carter, Mitchel, & Sbrocco, 2012). Hatch, Friedman, and Paradis (1996) and Williams, Chambliss, and Steketee (1998) presented case reports where exposure with response prevention (ERP) was found to be effective for African Americans suffering from OCD. Similarly, Friedman et al. (2003) conducted the only study to date to compare OCD treatment outcomes across ethnic groups. Employing a naturalistic design, the authors compared 26 adult African or Caribbean American participants with 36 European Americans and found that both ethnic groups made comparable gains with ERP treatment. To our knowledge, to date, no studies of this kind have focused on children and adolescents or have included individuals from other ethnic minority backgrounds.

It has been suggested that one of the reasons that could explain the inequalities in the use of services is that clinicians find it difficult to detect the symptoms of OCD in ethnic minorities (Fernández de la Cruz et al., 2014; Williams et al., 2010) due to slight differences in the phenomenological and clinical presentation of OCD in different ethnic groups (Guarnaccia, 1997; Hatch et al. 1996; Karadag, Oguzhanoglu, Ozdel, Atesci, & Amuk, 2006). Specifically, it has been reported that Black Americans may have a later age of onset (31.8 years vs. 19.5 years in the general population; Himle et al., 2008) and a different clinical presentation of the symptoms, such as greater contamination concerns (Wheaton, Berman, Fabricant, & Abramowitz, 2013; Williams, Abramowitz, & Olatunji, 2012; Williams, Turkheimer, Magee, & Guterbock, 2008; Williams, Turkheimer, Schmidt, & Oltmanns, 2005). Furthermore, it has been suggested that patients from ethnic minorities (mostly individuals from African-American backgrounds) with the most severe form of the disorder, especially those with uncommon symptoms, may be misdiagnosed as psychotic (Hollander & Cohen, 1994; Ninan & Shelton, 1993). It has also been suggested that the expression of OCD and attitudes toward the disorder may be influenced by religious beliefs and concerns, especially when referred to obsessions of religious and sexual nature (Karadag et al., 2006).

The aim of this naturalistic study was two-fold. First, we wanted to compare the clinical characteristics of a sample of White vs. non-White children and adolescents with OCD treated at a national specialist clinic in the UK. Better characterization of the phenomenology of OCD in children and adolescents from ethnic minorities might provide a more accurate picture of their symptoms and eventually help guide the diagnostic and assessment processes. Despite the differences in the clinical presentation of OCD between ethnic groups that have been reported in the above-mentioned studies, our clinical experience and similar work conducted in adults (Friedman et al., 2003) led us to hypothesize more similarities than differences in the clinical presentation of OCD in White vs. non-White youths. Second, we aimed to test whether the outcomes of a multimodal, evidence-based treatment

for OCD were comparable in both groups. We predicted that youths with OCD would respond well to the multimodal treatment, regardless of their ethnic group. Should this hypothesis be refuted, it could help understand the very low service utilization by youth from ethnic minorities.

## 2. Materials and methods

### 2.1. Procedures and participants

Participants were 207 youth meeting diagnostic criteria for OCD consecutively referred to and treated at the National and Specialist OCD and Related Disorders Team at the Maudsley Hospital, London. Detailed sociodemographic and clinical information was gathered from the patients and their parents as part of clinical practice. Diagnoses were made according to ICD-10 criteria by a multidisciplinary clinical team specializing in the diagnosis and management of OCD. For further details on the assessment process, please see Nakatani et al. (2011). Approval for the study was received from the South London and Maudsley Clinical Audit and Effectiveness Committee.

One hundred and sixty-nine individuals identified themselves as belonging to a White ethnic background (including 135 British, 28 English, and 6 'other White' individuals) and 35 to a non-White ethnic background (including 14 Mixed, 8 Black, 6 Asian, and 7 'other ethnic minority' individuals). Three additional patients did not state their ethnic group and were excluded from the analyses. The mean age of the final sample ( $N=204$ ) was 14.2 years ( $sd=2.3$ , range 8–18) and 47.5% were female. The mean score in the Children's Yale Brown Obsessive Compulsive Scale (CY-BOCS) was 26.1 ( $sd=5.6$ , range 10–39), which is in the moderate range of severity. Thirty percent were on medication for their OCD. Twenty-one percent had a comorbid diagnosis.

### 2.2. Measures

The CY-BOCS and its accompanying symptom checklist (CY-BOCS-SC), a list of more than 50 common obsessions and compulsions organized under 13 major symptom categories plus two categories of miscellaneous obsessions and compulsions, were carefully administered to the children and adolescents by a trained psychologist on the day of the initial assessment at the clinic to quantify the severity and detailed phenomenology of OCD symptoms, respectively (Gallant et al., 2008; Scahill et al., 1997). The CY-BOCS has shown high internal consistency and inter-rater agreement (Scahill et al., 1997). Similarly, the CY-BOCS-SC has demonstrated fair psychometric properties, including acceptable convergent and discriminant validity (Gallant et al., 2008). The CY-BOCS was re-administered at the end of treatment as the main outcome measure.

The Children's Obsessive-Compulsive Inventory (ChOCI) is a self- and parent-report instrument developed to assess obsessive-compulsive symptoms and their impairment in young people. The ChOCI has shown good internal consistency and criterion validity (Shafraan et al., 2003; Uher, Heyman, Turner, & Shafraan, 2008).

The Family Accommodation Scale (FAS) assesses the degree to which family members have accommodated the child's OCD symptoms and the level of distress or impairment that the family members and patient experience as a result (Calvocoressi et al., 1995). The FAS has adequate internal consistency and good inter-rater reliability (Calvocoressi et al., 1999).

The Children's Global Assessment Scale (CGAS) is a global measure of functional impairment that is associated with the presence of psychopathology. It has been found to be reliable between raters and across time and has demonstrated both discriminant and concurrent validities (Shaffer et al., 1983).

The Beck Depression Inventory for Youth (BDI-Y) is a widely used measure of depression, which has good internal consistency and test-criterion validity (Beck, Beck, & Jolly, 2001).

The Strengths and Difficulties Questionnaire (SDQ) assesses psychological adjustment of children and adolescents. Many studies from diverse countries have supported its validity and clinical utility (Goodman, 2001).

### 2.3. Treatment

All participants received cognitive-behavior therapy (CBT) from experienced therapists or trainees under close supervision. CBT was protocol-driven and largely focused on ERP, with parental involvement. It involved the following key components: psycho-education about OCD and anxiety; development of an exposure and response prevention hierarchy; graded exposure with response prevention; and relapse prevention. In most cases, 12–14 sessions were offered. Typically, sessions were weekly and 1-hour long. The treatment manual has been tested in several randomized controlled trials (Mataix-Cols et al., 2014; Turner et al., 2014). Sixty-two participants (30.4%) received medication for OCD (serotonin reuptake inhibitors [SRI]) in addition to CBT.

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