

# Evaluating Functional Impairment in Tourette Syndrome

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**Introduction:** Tourette Syndrome (TS) is the most common childhood-onset movement disorder and is characterized by multiple vocal and motor tics. TS is also associated with many behavioral comorbidities, most commonly Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (OCD). Patients with TS experience a wide level of functional impairment related to tics and comorbidity. The mini Child Tourette Syndrome Impairment Scale (mCTIM) is a clinical tool for rating functional impairment in patients with TS. To date, studies evaluating this scale have been distributed on paper forms with low response rates. The objective of this study was to understand and compare functional impairment in school, home, and social domains using a larger more representative sample in order to inform treatment of patients with TS.

**Methods:** All participants were youth referred for evaluation and management of tics to a children's hospital with a local and regional referral base. This dataset is the first 12 months of questionnaire data collected utilizing tablets provided to all families at clinical intake, including mCTIM ratings from parents (all) and patients (ages  $\geq 10$ ). Ratings from the mCTIM were linked with demographic data, Yale Global Tic Severity Scale (YGTSS) score, comorbid diagnoses, and ADHD and OCD rating scales. Descriptive statistics were used to compare scale domains and groups of interest after testing for normality to determine if parametric or non-parametric statistics were appropriate.

**Results:** All patients with a clinical diagnosis of TS were included (n=256; 88 female; 148 child [ages < 13 years]). Both parent-reported and self-reported impairment in patients with TS was worse in the school domain when compared to the home ( $P < 0.001$ ) or social ( $P < 0.001$ ) domain. Impairment related to non-tic behaviors (behavioral comorbidities) was worse than tic-related impairment in the school (parent-reported  $P < 0.001$ , self-reported  $P = 0.006$ ) and home (parent-reported  $P < 0.001$ , self-reported  $P = 0.01$ ) domains. Adolescents showed more impairment in the school domain than children in both the self-reported ( $P = 0.05$ ) and parent-reported ( $P = 0.008$ ) tic-related categories, although impairment scores declined significantly in older adolescents ( $R = -0.23$ ,  $P = 0.02$ ). Patients with comorbid ADHD, OCD or ADHD + OCD showed significantly worse impairment across all domains when compared with patients with TS and no comorbidities.

**Conclusion:** Treatment of patients with TS is complicated and multi-faceted so gaining insight on functional impairment in these patients is a key factor in increasing quality of life for each individual patient. Patients with TS may need care focused on school related activities, specifically as they near the age of 13. Extra attention must be given to patients who experience behavioral comorbidities, who may need to receive extra care across all domains.

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