

# Prevalence of Tourette Syndrome and Chronic Tics in the Population-Based Avon Longitudinal Study of Parents and Children Cohort

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**Objective:** Recent epidemiologic studies have demonstrated that Tourette syndrome (TS) and chronic tic disorder (CT) are more common than previously recognized. However, few population-based studies have examined the prevalence of co-occurring neuropsychiatric conditions such as obsessive-compulsive disorder (OCD) and attention-deficit/hyperactivity disorder (ADHD). We evaluated the prevalence of TS, CT, and their overlap with OCD and ADHD in the Avon Longitudinal Study of Parents and Children (ALSPAC) birth cohort. **Method:** A total of 6,768 children were evaluated using longitudinal data from mother-completed questionnaires. *DSM-IV-TR* diagnoses of TS and CT were derived using three levels of diagnostic stringency (Narrow, Intermediate, and Broad). Validity of the case definitions was assessed by comparing gender ratios and rates of co-occurring OCD and ADHD using heterogeneity analyses. **Results:** Age 13 prevalence rates for TS (0.3% for Narrow; 0.7% for Intermediate) and CT (0.5% for Narrow; 1.1% for Intermediate) were consistent with rates from other population-based studies. Rates of co-occurring OCD and ADHD were higher in TS and CT Narrow and Intermediate groups compared with controls but lower than has been previously reported. Only 8.2% of TS Intermediate cases had both OCD and ADHD; 69% of TS Intermediate cases did not have either co-occurring OCD or ADHD. **Conclusions:** This study suggests that co-occurring OCD and ADHD is markedly lower in TS cases derived from population-based samples than has been reported in clinically ascertained TS cases. Further examination of the range of co-occurring neuropsychiatric disorders in population-based TS samples may shed new perspective on the underlying shared pathophysiology of these three neurodevelopmental conditions. *J. Am. Acad. Child Adolesc. Psychiatry*, 2012;51(2):192–201. **Key Words:** Tourette syndrome, prevalence, ALSPAC, obsessive-compulsive disorder, attention-deficit/hyperactivity disorder

**T**ourette syndrome (TS) is a chronic, childhood-onset neuropsychiatric disorder characterized by waxing and waning motor and vocal tics that persist for more than 1 year.<sup>1</sup> Tics usually begin between 5 and 7 years of age, are most severe in early adolescence, and then gradually decrease in early adulthood.<sup>2,3</sup> Chronic tic disorder (CT), which is defined by the presence of either motor or vocal tics (but not both), is similar in clinical phenomenology and disease

course to TS, but is less frequently associated with co-occurring neuropsychiatric conditions, such as obsessive-compulsive disorder (OCD) and attention-deficit/hyperactivity disorder (ADHD).<sup>4</sup> TS and CT cause significant physical and psychosocial morbidity, and in severe cases can produce lifelong disability.<sup>2,5</sup>

TS was initially considered to be rare, with early estimates of approximately 5 per 10,000 school-age children (0.05%).<sup>6</sup> However, these studies included only clinically ascertained cases, an approach that greatly underestimates the true prevalence of the disorder by excluding individuals who do not seek treatment. In contrast, a



Supplemental material cited in this article is available online.

number of population-based studies have been conducted over the past two decades that suggest that TS is much more common, with most prevalence estimates converging around a rate of 0.3% to 0.8% of the school-age population.<sup>7,8</sup> Fewer studies have examined the prevalence of CT, and estimates range from 1.3% to 3.7% of children.<sup>9-11</sup> Determination of accurate TS/CT prevalence estimates is important for assessing the overall burden of disease, allocating treatment resources, and estimating the familial risk in relatives of TS patients.

In addition, TS and CT are frequently associated with multiple co-occurring neuropsychiatric conditions in clinically ascertained samples, particularly OCD and ADHD. In the largest clinical study of 3,500 TS patients from 64 international clinics, OCD was present in 27% (range 2%–66%), whereas 60% had ADHD (range 33%–91%).<sup>12</sup> Furthermore, only 12% of TS patients (range 2%–35%) had tics without any other co-existing disorders.<sup>12</sup> A more recent U.S. telephone-based survey of clinician-diagnosed TS found that 64% of children with TS had ADHD and 79% had at least one co-occurring neuropsychiatric condition.<sup>13</sup> Although these clinic-based estimates are important for informing clinical practice, they may overestimate the true rates of co-occurring disorders with TS in the general population because of referral bias. Various studies have examined rates of TS-related OCD and/or ADHD in the general population.<sup>4,14-20</sup> Some of these studies suggest that community-based TS subjects have lower rates of OCD<sup>4,17,19</sup> (0%–19%) and ADHD<sup>15</sup> (8%) than cases ascertained through clinics, although others are consistent with rates found in clinical populations (42% for OCD<sup>15</sup> and 36%–100% for ADHD).<sup>4,14,16,17,19,20</sup> In addition, only one of these population-based studies examined concurrent OCD and ADHD in CT specifically,<sup>4</sup> although other studies have examined rates of ADHD across the tic spectrum.<sup>7,21</sup> A more comprehensive understanding of the relationship and overlap between TS/CT, OCD, and ADHD in the general population would provide a framework for studies of the underlying genetics and pathophysiology of these disorders.

Here, we determined the prevalence of TS and CT, as well as the rates of co-occurring OCD and ADHD, in the Avon Longitudinal Study of Parents and Children (ALSPAC) sample, an ongoing, prospective, population-based birth cohort study in which tic, OCD, and

ADHD symptoms were assessed by maternal screening questionnaires at multiple time points throughout childhood.

## METHOD

### Subjects

A total of 14,541 pregnant women resident in Avon, United Kingdom, with expected delivery dates between April 1, 1991, and December 31, 1992, were enrolled in ALSPAC, representing 85% of the eligible population.<sup>22,23</sup> Of the 14,472 pregnancies with known birth outcomes, 13,988 infants were alive at 1 year. Mothers completed self-administered questionnaires about themselves and their child's development, environmental exposures, and health outcomes approximately every 6 months from birth to age 7 years and every year thereafter, with data available for 7,152 children at age 13. 99% of children were between 13 years 1 month and 13 years 11 months of age at the time the age 13 questionnaire was answered (full range: 12 years 10 months to 16 years 1 month). Ethical approval for the study was obtained from the ALSPAC Law and Ethics Committee and Local Research Ethics Committees. The characteristics of this population-based sample and its generalizability have been previously reported.<sup>22</sup> Briefly, children in Avon had parents with a similar racial distribution as the general UK population (5.1% versus 6.4% nonwhite, in Avon and the entire United Kingdom, respectively), level of education (14.0% vs 13.7% with university degrees), and the rate of single parent households at age 5 (4% versus 5%), although children in Avon were significantly less likely to have a father working in manual labor (51.6% versus 65.1%).

### Disease Definitions

ALSPAC children were evaluated for the presence of a tic disorder in nine mother-completed questionnaires from age 1.5 to 13 years (questionnaires are available at the ALSPAC Web site at <http://www.bristol.ac.uk/alspac/sci-com/quests/>). At yearly intervals from age 1.5 to 7.5 years and at age 10, mothers were asked a single screening question about the presence and frequency of "tics or twitches" in their child. Rates of positive response to this single tic question at each age are provided online (Table S1, available online). At age 13 years, a more detailed tic assessment was administered, including a section with five questions about specific motor and vocal tics: (C1: In the past year, has your child had any repeated movements of parts of the face and head (e.g., eye blinking, grimacing, sticking tongue out, licking lips, spitting)?; C2: Has your child had repeated movements of the neck, shoulder or trunk (e.g., twisting around, shoulder shrugging, bending over, nodding)?; C3: Has your child had repeated movements of arms, hands, legs, feet?; C4: Has your child had repeated noises and sounds (e.g., coughing, clearing throat, grunting, gurgling,

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