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## Children with Tourette Syndrome in the United States: Parent-Reported Diagnosis, Co-Occurring Disorders, Severity, and Influence of Activities on Tics

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### Abstract

**Objective:** Describe the diagnostic process for Tourette syndrome (TS) based on parent report, as well as TS severity and associated impairment; the influence of common daily activities on tics; and the presence of co-occurring mental, behavioral, and developmental disorders among children in the United States.

**Methods:** Parent-report data from the 2014 National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome on 115 children ever diagnosed with TS were analyzed. Descriptive, unweighted analyses included frequencies and percentages, and means and standard deviations. Fisher's exact test and *t*-tests were calculated to determine statistically significant differences.

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**Results:** The mean age that tics were first noticed was 6.3 years, and, on average, TS was diagnosed at 7.7 years. The time from initially noticing tics to TS diagnosis averaged 1.7 years. The mean age when TS symptoms were most severe was 9.3 years. Tic severity was associated with impaired child functioning but not tic noticeability. Almost 70% of parents reported that fatigue and major transitions made their child's tics worse. Children with ever-diagnosed TS had a mean of 3.2 ever-diagnosed co-occurring mental, behavioral, or developmental disorders; a quarter (26.9%) had 5 or more co-occurring disorders.

**Discussion:** In this sample of children with TS, the time to diagnosis averaged less than 2 years from when tics were initially noticed. More severe TS was associated with greater functional impairment, and co-occurring disorders were common among children with TS. This study provides insight into the current experiences of children with TS in the United States and their families.

Tourette syndrome (TS) is a tic disorder characterized by multiple motor tics and at least 1 vocal tic that begin during childhood; tics must persist for more than 1 year, although tics may change and wax and wane over the year.<sup>1</sup> Tics are involuntary, repetitive movements and vocalizations that are usually sudden and rapid. The average age of onset for tic disorders, including TS, is 4 to 6 years.<sup>2</sup> A 2015 meta-analysis based on a subset of studies that did not rely on a previous tic disorder diagnosis suggested a population estimate of 0.52% for TS among children aged 4 to 18 years.<sup>3</sup> Based on parent-reported data from the 2011–2012 National Survey of Children's Health (NSCH), TS had been diagnosed by a healthcare professional in 0.28% of children aged 6 to 17 years in the United States (U.S.).<sup>4</sup> The difference between estimates based on the NSCH, which relies on previous diagnoses, versus studies that include previously unidentified cases suggests a continued need to explore the diagnostic process and characteristics of TS.<sup>5</sup>

The etiology of TS and other tic disorders is strongly familial,<sup>6</sup> but the onset is likely influenced by an interaction of genetics and environment,<sup>7</sup> including perinatal factors<sup>8,9</sup> or stressful life events<sup>10</sup>; infections have also been explored as a potential cause of tics.<sup>11</sup> The impact of the condition can include impairment in daily functioning,<sup>12</sup> greater psychosocial stress,<sup>13</sup> and difficulties with peers.<sup>14</sup> TS is also associated with an increased risk for family and marital conflicts,<sup>15</sup> parenting aggravation,<sup>16</sup> and problems at school.<sup>17</sup>

Tic severity varies by individual and over time.<sup>5,18</sup> In a series of studies of children aged 5 to 19 years, TS was often described as mild,<sup>5,18</sup> and severity steadily declined during adolescence.<sup>2,18</sup> In a large prospective clinical study by Groth et al.,<sup>19</sup> the majority of children with TS at baseline no longer had tics or had minimal to mild tics by 16 years of age. Co-occurring mental, behavioral, and developmental disorders are common with TS, with previous studies suggesting that approximately 80% to 90% of individuals with TS have had at least 1 co-occurring disorder.<sup>4,20,21</sup> Two of the most common co-occurring disorders are attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder.<sup>2,14,20,21</sup> When compared to children with only a TS diagnosis, children with both TS and a co-occurring mental, behavioral, or developmental disorder(s) often have exacerbated impairment in multiple domains (e.g., at school, socially, with family).<sup>14,21</sup> The many complexities of TS including variability of symptoms,<sup>5,18</sup> evolving nature of tic

expression and severity,<sup>5,18,19</sup> and increased risk for co-occurring disorders<sup>4,20</sup> highlight the importance of improving our understanding of this condition to inform efforts that support children living with TS and their families.<sup>22</sup>

The vast majority of studies dedicated to children with TS consist of samples recruited from clinical populations and, therefore, are limited to a single geographic area.<sup>7,10,23,24</sup> There is a lack of studies investigating the diagnostic and treatment experiences of children with TS from geographically diverse, non-clinically drawn samples. The National Survey of the Diagnosis and Treatment of ADHD and TS, designed to improve knowledge related to specific aspects of TS and ADHD,<sup>25</sup> provides such an opportunity. The goals of this paper are to describe the diagnostic process from tic onset to TS diagnosis; report the percent of co-occurring mental, behavioral, and developmental disorders; describe the severity of TS and associated impairment; and characterize the influence of tics on the daily lives and activities of children living with TS and their families.

## METHODS

Data for this analysis come from the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome (NS-DATA), which was conducted in 2014 by the National Center for Health Statistics, with support from the U.S. Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities. NS-DATA combines experiences of children with attention-deficit/hyperactivity disorder (ADHD) and Tourette syndrome (TS) from across the United States; thus, the survey is not limited to a single geographic region, state, clinic, or healthcare provider. NS-DATA is a follow-up survey to the 2011–2012 National Survey of Children's Health (NSCH), a U.S.-based, nationally representative survey that used random-digit-dialing to landline and cell phones to identify households with children. The 2011–2012 NSCH was designed to examine the physical and emotional health of children aged 0 to 17 years in the United States.<sup>25,26</sup> Both surveys (2011–2012 NSCH and 2014 NS-DATA) were completed by a parent or guardian (herein referred to as “parent”) who was familiar with the selected child's health and healthcare, but the NS-DATA parent respondent could be different from the NSCH respondent for a child. The eligible sample for NS-DATA included households where the parent reported that the selected child had ever been diagnosed with TS or ADHD by a doctor or healthcare provider at the time of the 2011–2012 NSCH.<sup>26</sup> NS-DATA was conducted from January 2014 to June 2014, 2 to 3 years after the 2011–2012 NSCH was administered, with an average time lapse of 29 months between the 2 surveys.<sup>25</sup> Additional eligibility criteria included that, at the time of NS-DATA, the parent reported that the selected child was under the age of 18 years, lived in the same household, and had ever been diagnosed with TS or ADHD.<sup>25</sup> The child did not need to have current TS or ADHD at the time of NS-DATA.

The National Survey of the Diagnosis and Treatment of ADHD and TS included 2 modules, 1 for parents of children ever diagnosed with TS and the other for parents of children ever diagnosed with ADHD. Parents of children who were ever diagnosed with both disorders could complete both modules. Parents of 78 children who were reported to have a TS diagnosis at the time of the 2011–2012 NSCH completed the TS module of NS-DATA in

2014. Additionally, there were 37 children who were reported to have an ADHD diagnosis on the 2011–2012 NSCH whose parent also reported a TS diagnosis when they were contacted to participate in the NS-DATA ADHD module. This results in a maximum sample size for this study of 115 respondents. Figure 1 shows the progression of participants identified as ever having been diagnosed with TS in the 2011–2012 NSCH to the 2014 NS-DATA. This analysis focuses on the TS module of NS-DATA, which includes detailed questions asked of parents about their child’s experience with TS and its impact on their family, treatment options, and educational experiences. Accessing the TS module of NS-DATA requires a data agreement with the National Center for Health Statistics’ Research Data Center. The ADHD module dataset of NS-DATA is publically available. More information about accessing the NS-DATA datasets can be found at [www.cdc.gov/nchs/slaits/ns\\_data.htm](http://www.cdc.gov/nchs/slaits/ns_data.htm) and [www.cdc.gov/rdc](http://www.cdc.gov/rdc).

For this analysis, we examined parent-reported data regarding the TS diagnostic process, the severity of TS and associated impairment, the influence of common childhood activities on tics, and the presence of co-occurring mental, behavioral, and developmental disorders. All of the information collected by NS-DATA is based on parent report. All age variables were reported in whole years. For participant confidentiality, outcomes with any potential disclosure risk (e.g., small cell values of observable responses) were either collapsed into other categories or not presented. Any responses of “don’t know,” “other,” or refusal to answer the question were classified as missing; additional values classified as missing are described below. Several indicators had missing data for a large number of respondents (greater than 10 observations).

Questions regarding TS diagnosis included child’s age when tics were first noticed, child’s age when the parent first asked a doctor for help because of the tics, child’s age at the time of TS diagnosis, number of doctors or healthcare providers seen about the tics leading up to the diagnosis, and type of provider who made the TS diagnosis. The time from first noticing the tics to diagnosis was calculated by subtracting the child’s age when tics were first noticed from the child’s age when TS was diagnosed. The time to TS diagnosis was calculated by subtracting the child’s age when the parent first asked a doctor for help because of the tics from the child’s age when diagnosed with TS. The number of years with diagnosed TS was similarly calculated for children with current TS at the time of NS-DATA by subtracting the child’s age at diagnosis from the child’s age at the time of the survey. Implausible values (e.g., age of first noticing tics was greater than age at diagnosis) were excluded from the time interval calculations. Parents were also asked which type of tic (e.g., motor tic only, vocal tic only, or both motor and vocal tics) was initially noticed; if they believed their child’s tics were caused by a stressful life event; and if they believed tics were caused by an infection, such as strep throat.

Parents were asked to rate the severity of their child’s current TS (asked only of parents of children currently diagnosed with TS), as well as the severity of their child’s TS when the symptoms were at their worst (asked of all parents). Parents could choose from “mild,” “moderate,” or “severe.” Parents were asked if TS symptoms, when at their worst, were noticeable to strangers, and if TS symptoms interfered with their child’s ability to do things that other children could do.

Parents reported on whether 11 common childhood activities influenced their child's tics. Questions asked included how the child's tics were influenced by the following 9 daily activities: "being tired," "talking about tics," "doing homework," "playing team sports," "playing video games or other computer games," "watching television (TV)," "exercising or doing an individual sport," "performing quiet hobbies," and "playing music or singing" and 2 transitions: "major transitions, like starting a new school or moving to a new classroom" and "minor transitions, like switching activities or changing locations." For each question, the parent indicated if the activity made tics "better," "worse," or had "no impact." The parent could have also answered "depends," "child does not do that activity," "not applicable," "don't know," or refused to answer the question, but those responses were coded as missing for the analysis. We limited our analysis of these questions to children with current TS (n = 82) at the time of NS-DATA because these questions were only asked about children with current TS or tics at the time of NS-DATA (we excluded participants who indicated "yes" to their child currently having tics but did not indicate "yes" to their child currently having TS (n = 11) due to the focus of the manuscript on TS rather than another tic disorder).

Finally, we examined parents' report of other diagnosed mental, behavioral, and developmental disorders. The survey asked specifically about the following 15 disorders: ADHD, anxiety disorder (such as generalized anxiety, panic disorder, or a phobia), autism spectrum disorder or pervasive developmental disorder, bipolar disorder, conduct disorder, eating disorder (such as anorexia or bulimia), intellectual disability, intermittent explosive disorder, language disorder, learning disorder, mood disorder (such as depression or major depressive disorder), obsessive-compulsive disorder, oppositional defiant disorder, post-traumatic stress disorder, and substance use disorder. For each disorder, parents were asked, "Has a doctor or health care provider ever told you that [your child] had [specified disorder]?" If the parent indicated "yes," the parent was then asked if their child currently had that specified disorder. Parents had to answer "yes" to both questions for the child to be coded as currently having the specified disorder. If the parent refused to answer or indicated "don't know" to both questions, the selection was coded as missing for both ever diagnosed and current diagnosis. For this part of the analysis, we restricted our analysis to the 78 children who were originally identified with TS at the time of the 2011–2012 NSCH. Along with reporting the frequency and percent of co-occurring disorders, we enumerated each disorder and calculated the frequencies and mean number of co-occurring disorders overall and by demographic and TS-related characteristics. To reduce disclosure risk, the frequency of conduct disorder and eating disorder were not presented individually, and bipolar disorder, intermittent explosive disorder, and substance use disorder were grouped together; however, each of these disorders was counted individually for the calculation of the mean number of co-occurring disorders among children with TS.

### Statistical Analysis

Data were treated as a convenience sample for the analyses. We present an unweighted descriptive analysis with the frequencies and percentages or the mean and SD, as appropriate. All statistical comparisons were made using the Fisher's exact test or *t*-test with

$p < 0.05$  to indicate a statistically significant difference. We performed these analyses in SAS version 9.3 (RTI International; Cary, NC).

## RESULTS

### Sample Characteristics

Among the 115 children in the Tourette syndrome (TS) module of National Survey of the Diagnosis and Treatment of ADHD and TS (NS-DATA), most were male (82.6%,  $n = 95$ ) and non-Hispanic white (70.4%,  $n = 81$ ). Three-fourths (74.8%,  $n = 86$ ) had at least 1 parent who attended some college or more. The mean age of children at the time of NS-DATA was 13.2 years ( $SD = 2.9$ ), with 39.1% ( $n = 45$ ) of the children between the ages of 5 and 12 years. The TS module of NS-DATA included children from 44 of the 50 U.S. states.

### Time to Diagnosis, Diagnosing Healthcare Provider, and Perceived Cause of Tics

Most parents (82.3%,  $n = 93$ ) reported noticing their child's tics by 8 years of age, with a mean age of 6.3 years ( $SD = 2.6$ ). Parents who reported their child's first tics as vocal-only noticed the tics about a year earlier (mean age 5.5 years,  $SD = 1.9$ ) than parents who reported their child's first tics as motor-only (mean age 6.6 years,  $SD = 2.5$ ) or as both vocal and motor (mean age 6.8 years,  $SD = 2.8$ ). Parents reported first asking a doctor or healthcare provider for help with the tics when the child was 7.1 years old on average ( $SD = 2.7$ ). The mean age at TS diagnosis was 7.7 years ( $SD = 2.7$ ).

The mean amount of time from when tics were first noticed to TS diagnosis was 1.7 years ( $SD = 1.6$ ). On average, the time to diagnosis, calculated by subtracting the age of first asking a healthcare provider for help with tics from the age of diagnosis, was 1 year (1.0 years,  $SD = 1.5$ ). Nearly half (49.6%,  $n = 56$ ) of parents reported their child was diagnosed with TS by the first (20.4%) or second (29.2%) healthcare provider they saw about the tics, the other half (50.4%,  $n = 57$ ) reported seeing 3 or more providers before receiving a TS diagnosis. There was no difference in the mean time to diagnosis by the number of providers seen about the tics (1 or 2 vs 3 or more providers). The majority (51.8%,  $n = 58$ ) of children were diagnosed with TS by a specialty healthcare provider (i.e., neurologist, psychiatrist, or developmental and behavioral pediatrician), followed by 31.3% ( $n = 35$ ) diagnosed by a general healthcare provider (i.e., pediatrician or family practice doctor), and the remaining by a psychologist outside of their school, a multidisciplinary team of healthcare professionals, or other healthcare provider (17.0%,  $n = 19$ ).

Over one-fourth (29.1%,  $n = 30$ ) of parents believed that tics were caused by a stressful life event, 5.9% ( $n = 6$ ) believed that tics were caused by an infection such as strep throat. For these 2 questions, 12 parents indicated "don't know" about tics being caused by a stressful life event, and 14 responded "don't know" about an infection causing their child's tics.

### Symptom Severity and Associated Impairment

One-fifth of parents described their child's TS severity when at its worst as "mild" (19.1%,  $n = 22$ ), just over half as "moderate" (53.9%,  $n = 62$ ), and the remaining as "severe" (27.0%,  $n = 31$ ). The mean age when TS was most severe was 9.3 years ( $SD = 2.9$ ). The majority

(92.9%,  $n = 105$ ) of parents reported that when tics were most severe, they were noticeable to strangers, and more than half (55.8%,  $n = 63$ ) reported tics interfered with the child's ability to do things that other children could do. Figure 2 compares the worst TS severity ("mild" and "moderate" vs "severe") by noticeability of tics to strangers and interference of tics with the child's functioning. Children with "severe" TS were more likely to have tics that interfered with their functioning as compared to children with "mild" or "moderate" TS, and this was statistically significant ( $p < 0.05$ ).

### **Description of Children with Current Tourette Syndrome at the Time of the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome**

Children with current TS ( $n = 82$ ) at the time of NS-DATA received their initial diagnosis an average of 5.7 years ( $SD = 3.1$ ) prior to NS-DATA, calculated by subtracting the child's age at TS diagnosis from the child's age at the time of NS-DATA. The majority of parents described their child's current TS severity as "mild" (63.4%,  $n = 52$ ). The remaining children were described as currently having "moderate" (28.1%,  $n = 23$ ) or "severe" (8.5%,  $n = 7$ ) TS. Children with "mild" current TS had a mean age of 13.5 years ( $SD = 2.4$ ), and children with current "moderate" or "severe" TS had a mean age of 12.9 years ( $SD = 3.3$ ); this difference was not statistically significant.

### **Influence of Childhood Activities on Tics**

Figure 3 displays how common day-to-day activities influence tics among children with current TS at the time of NS-DATA ( $n = 82$ ). The majority of parents reported that "experiencing major transitions" (69.2%,  $n = 54$ ) and "being tired" (67.9%,  $n = 55$ ) made tics worse. A large percentage of parents reported that "performing other quiet hobbies" (50.0%,  $n = 38$ ) and "exercising or doing an individual sport" (45.5%,  $n = 35$ ) made their child's tics better. Other activities, including "experiencing minor transitions," "watching TV," "doing homework," "talking about tics," "playing music or singing," "playing team sports," and "playing video games or other computer games," were reported to have no impact on tics by about half or more (range of 44.0%–70.0%) of the parents.

### **Prevalence of Co-Occurring Mental, Behavioral, and Developmental Disorders**

Of the 78 children initially identified as ever having been diagnosed with TS at the time of the 2011–2012 National Survey of Children's Health, the majority (84.6%,  $n = 66$ ) had also ever been diagnosed with at least one other mental, behavioral, or developmental disorder at the time of NS-DATA (Table). The most common ever-diagnosed co-occurring disorders were attention-deficit/hyperactivity disorder (62.8%,  $n = 49$ ), anxiety disorder (44.9%,  $n = 35$ ), obsessive-compulsive disorder (42.3%,  $n = 33$ ), and mood disorders, such as depression (34.6%,  $n = 27$ ). The mean number of ever-diagnosed co-occurring disorders per child was 3.2 disorders ( $SD = 2.6$ ). Over a quarter (26.9%,  $n = 21$ ) of the children had ever been diagnosed with 5 or more co-occurring disorders. Females had a mean of 3.9 ever-diagnosed co-occurring disorders ( $SD = 3.0$ ), and males had a mean of 3.1 disorders ( $SD = 2.5$ ), although this difference was not statistically significant. The mean number of ever-diagnosed co-occurring disorders was significantly higher for children whose TS was "severe," averaging 4.5 co-occurring disorders ( $SD = 2.5$ ), compared to children whose TS was "mild" or "moderate," with an average of just under 3 co-occurring disorders (mean =

2.7,  $SD = 2.5$ ,  $p < 0.05$ ). Results for current co-occurring disorders among children ever diagnosed with TS show similar patterns to the ever co-occurring disorders and are also presented in Table 1. At the time of NS-DATA, children with current TS ( $n = 60$ ) averaged 3.4 ever-diagnosed co-occurring disorders ( $SD = 2.6$ ), and children without current TS had a mean of 2.7 ever-diagnosed co-occurring disorders ( $SD = 2.4$ ); this difference was not statistically significant (data not shown in Table).

## DISCUSSION

The results reported here, based on parent-reported data, highlight some of the complexities associated with Tourette syndrome (TS), including the time to diagnosis, TS symptom severity and related impairment, differing influence of childhood activities on tics, and the high percentage of children with other mental, behavioral, and developmental disorders as well as TS. Although previous studies have reported time to diagnosis ranging from 4 to 6.5 years,<sup>21,27</sup> we estimated that the time from tics first being noticed to TS diagnosis averaged 1.7 years. The time interval from first seeing a healthcare provider about the tics to TS diagnosis averaged 1.0 year. Decreasing the time to diagnosis has been shown to increase access to needed treatment, support, and services.<sup>22,28</sup> The shorter time to diagnosis identified in our study is similar to findings from more recent studies in Europe and Asia.<sup>23,28</sup> However, our analysis also showed that half of the families (50.4%) saw 3 or more healthcare providers before their child received a TS diagnosis, which may have varied effects on the time to diagnosis. On one hand, seeing a greater number of healthcare providers (e.g., referring the child to a specialist) may accelerate the time to diagnosis. On the other hand, seeing multiple providers may create additional barriers for the child and family, therefore contributing to delays in diagnosis. Regardless, continued monitoring and evaluation of the time to diagnosis of TS may be important given the association between delay in diagnosis and delay in treatment as noted by Hollis et al.<sup>28</sup>

Although most children's tics were noticeable to strangers (92.9%) regardless of symptom severity, children with severe TS were more likely to have tics interfere with functioning than children with mild or moderate TS. This finding suggests that parent-reported severity may indicate functional impairment due to TS rather than the appearance and noticeability of tics. While there has not yet been an in-depth evaluation of the parent-reported indicator of TS severity, an analysis of parent-reported severity for autism spectrum disorder found a parent's perception of their child's disorder severity was associated with the impact of the disorder on the family, more so than the symptoms exhibited by the child or direct impact of the disorder felt by the child.<sup>29</sup> It is important to consider that parent-reported severity and impairment may be influenced by the parent's experience of the disorder as well as the child's.

Our analysis of 11 common childhood activities, reflected in Figure 3, shows that the same activity (e.g., doing homework, playing team sports, playing video games) can make tics worse in one child and better in another, which has also been seen in other TS research.<sup>7,10,12</sup> Previous research has shown that efforts to educate the child and family about TS, including its impact across multiple settings (e.g., home, school, and socially), may improve tic symptoms among children with TS.<sup>30</sup>



Finally, in our analysis, most children (84.6%) with ever-diagnosed TS had one or more other ever-diagnosed mental, behavioral, or developmental disorder(s); over half had 3 or more co-occurring disorders, according to parent-report. Furthermore, children with severe TS had significantly more co-occurring disorders than children with mild or moderate TS. These results align with previous research showing that children with TS may have increased healthcare needs and may require additional mental health or educational services and support.<sup>17,31</sup> The Practice Parameter for the Treatment of Children and Adolescents with Tic Disorders by the American Academy of Child and Adolescent Psychiatry (Practice Parameter)<sup>30</sup> recommends healthcare providers perform a comprehensive assessment of children suspected with TS as the clinical standard.

The findings in this report are subject to several limitations. First, the data in this analysis come from a small convenience sample of parents of children ever diagnosed with TS or attention-deficit/hyperactivity disorder (ADHD) who were initially identified at the time of the 2011–2012 National Survey of Children’s Health (NSCH) and then successfully recontacted for participation in National Survey of the Diagnosis and Treatment of ADHD and TS (NS-DATA) (as described in Fig. 1). A comparison (data available upon request) of the 3 samples of the TS module of NS-DATA (i.e., the full sample [n = 115], those who identified as ever having TS at the time of both NSCH and NS-DATA [n = 78], and those who identified as ever having TS at the time of NS-DATA [n = 37]) did not reveal meaningful differences between the 3 samples, except for a higher prevalence of co-occurring disorders among those identified with TS when contacted for the ADHD module of NS-DATA (n = 37). Due to this difference, the analysis of co-occurring disorders was restricted to the 78 who identified as ever having TS at the time of both 2011–2012 NSCH and NS-DATA. The purpose of this study is not to estimate population values, and therefore the sample is treated as a convenience sample. Confidence intervals are not reported, and the results are not generalizable to the U.S. population of children who have been diagnosed with TS.

To be eligible for NS-DATA, children selected to be the subject of an NSCH interview had to have had a diagnosis of TS or ADHD at the time of the 2011–2012 NSCH interview. Therefore, these estimates may not reflect recent diagnostic practices for TS because most of the sample had been diagnosed with TS prior to the 2011–2012 NSCH. The diagnostic criteria for TS were changed slightly in the revision of the Diagnostic and Statistical Manual of Mental Disorders, published in 2013, although the changes were not expected to substantially change clinical practice.<sup>1,32</sup> The 37 children identified at the time of NS-DATA may include children who developed TS between NSCH and NS-DATA, but may also reflect children who had TS at the time of NSCH, but it was either undiagnosed or the parent did not report the diagnosis. Also, reports about the diagnostic experience that happened years in the past may be subject to recall bias.

National Survey of the Diagnosis and Treatment of ADHD and TS consists entirely of parent-reported indicators that have not been validated against medical records or a clinical assessment. NS-DATA did not collect child-reported data, which, in previous TS research, has shown a difference in quality of life measures when comparing child self-report to

parent-report.<sup>13</sup> Finally, the large number of missing respondents for various indicators on the survey may influence the results and conclusions drawn.

In conclusion, TS is a complex disorder that has implications for the daily lives of children living with TS, their families, and their communities. This analysis provides a unique, in-depth look at the experiences of children with TS from a geographically diverse, broadly drawn sample. This analysis, along with other TS research, reflects the complexities of TS and the challenges this disorder can present at an important period in a child's development. The evolving nature of symptoms and associated impairment, environmental influences on tics, and the high percentage of children diagnosed with co-occurring disorders all reinforce the importance of continued investigation of this disorder at a national level.<sup>22</sup>

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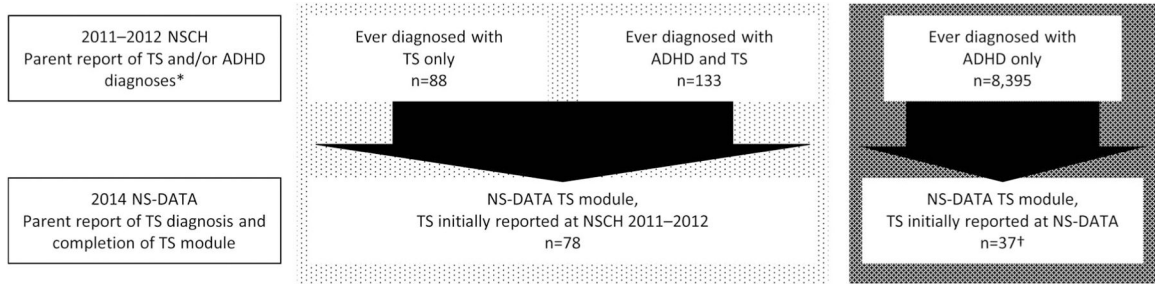
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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC.

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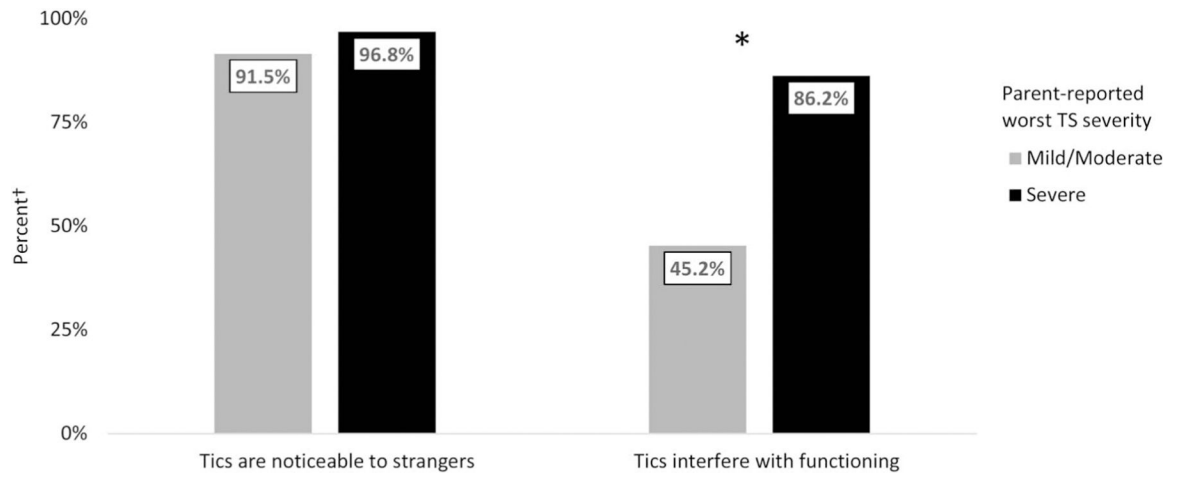
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**Figure 1.**

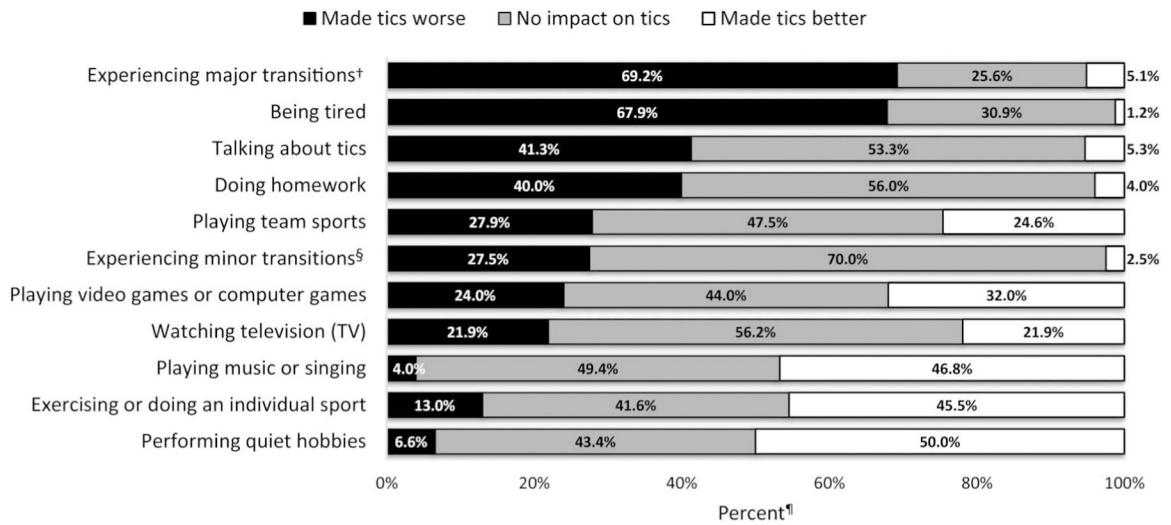
Progression of participants from the 2011–2012 NSCH to the 2014 NS-DATA Tourette syndrome module. ADHD, attention-deficit/hyperactivity disorder; NSCH, National survey of Children’s health; NS-DATA, National survey of the diagnosis and treatment of ADHD and Tourette Syndrome; TS, Tourette syndrome. \*Not all participants identified at 2011–2012 NSCH were eligible for NS-DATA, and not all eligible were recontacted. †This value represents the participants who were initially recontacted based on eligibility for the NS-DATA ADHD module only but at the time of NS-DATA reported their child had ever received a TS diagnosis and then qualified for and completed the NS-DATA TS module. Since they were sampled due to a previous parent report of ever having been diagnosed with ADHD, they were excluded from the analysis of co-occurring conditions, as their inclusion would inflate the estimated occurrence of co-occurring conditions among those with TS. Please see NS-DATA frequently asked questions for more details: [ftp://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/slaits/ns\\_data/NS\\_DATA\\_FAQs.pdf](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/slaits/ns_data/NS_DATA_FAQs.pdf).



**Figure 2.**

Tic noticeability and impairment by worst TS severity. Data from the 2014 NS-DATA. \*

Statistically significant at  $p < 0.05$ . † All percentages are unweighted. ADHD, attention-deficit/hyperactivity disorder; NS-DATA, National Survey of the Diagnosis and Treatment of ADHD and TS; TS, Tourette syndrome.



**Figure 3.** Influence of common childhood activities on tics among children with current TS\*. Data from the 2014 NS-DATA. \* Mean number of missing values among the 11 childhood experiences and activities was 6.7 observations (SD = 5.27), ranging from 1 to 21 missing observations per question. “Playing team sports” had the most missing; 16 parents said their “child did not do that activity” and the remaining 5 responded with either “depends,” or “don’t know.” † Major transitions (like starting a new school or moving into a new class). § Minor transitions (like switching activities or changing locations). ¶ All percentages are unweighted. ADHD, attention-deficity/hyperactivity disorder; NS-DATA, National Survey of the Diagnosis and Treatment of ADHD and TS; TS, Tourette syndrome.

**Table 1.**

Percentage of MBDDs Among Children Ever Diagnosed With Tourette Syndrome

| NS-DATA Participants Identified at the Time of NSCH, n = 78                |                |                      |              |                      |                      |                      |
|--|----------------|----------------------|--------------|----------------------|----------------------|----------------------|
|  | Ever Diagnosed |                      | Co-occurring |                      | Current Co-occurring |                      |
|  | n              | Percent <sup>b</sup> | n            | Percent <sup>b</sup> | n                    | Percent <sup>b</sup> |
| No. of diagnosed co-occurring MBDDs per child <sup>a</sup>                 |                |                      |              |                      |                      |                      |
| 0 co-occurring disorders   | 12             | 15.4                 | 16           | 20.5                 |                      |                      |
| 1 or more co-occurring disorders   | 66             | 84.6                 | 62           | 79.5                 |                      |                      |
| 3 or more co-occurring disorders   | 42             | 53.9                 | 32           | 41.0                 |                      |                      |
| 5 or more co-occurring disorders   | 21             | 26.9                 | 11           | 14.1                 |                      |                      |
| Percent of individual co-occurring disorders                               |                |                      |              |                      |                      |                      |
| ADHD   | 49             | 62.8                 | 36           | 50.7                 |                      |                      |
| Anxiety disorder, such as generalized anxiety, panic disorder, or a phobia | 35             | 44.9                 | 29           | 37.7                 |                      |                      |
| OCD  | 33             | 42.3                 | 28           | 36.4                 |                      |                      |
| Mood disorder, such as depression or major depressive disorder             | 27             | 34.6                 | 14           | 18.0                 |                      |                      |
| Learning disorder  | 22             | 28.6                 | 20           | 26.0                 |                      |                      |
| ODD  | 21             | 27.3                 | 10           | 13.0                 |                      |                      |
| Autism spectrum disorder or pervasive developmental disorder               | 19             | 24.4                 | 18           | 23.1                 |                      |                      |
| Language disorder  | 12             | 15.4                 | 8            | 10.3                 |                      |                      |
| Other low-frequency disorders <sup>c</sup>                                 | 10             | 12.8                 | 8            | 10.3                 |                      |                      |
| PTSD   | 9              | 11.5                 | 9            | 11.5                 |                      |                      |
| Intellectual disability  | 8              | 10.4                 | 8            | 10.4                 |                      |                      |

Data from the 2014 NS-DATA.

<sup>a</sup>These values are not mutually exclusive.

<sup>b</sup>All percentages are unweighted.

<sup>c</sup>Other low-frequency disorders include bipolar disorder, intermittent explosive disorder, substance use disorder. To ensure the confidentiality of participants, these disorders were collapsed due to low individual frequencies. ADHD, attention-deficit/hyperactivity disorder; MBDD, Mental, Behavioral, and Developmental Disorders; NSCH, National Survey of Children's Health; NS-DATA, National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome; OCD, obsessive-compulsive disorder; ODD, oppositional defiant disorder; PTSD, post-traumatic stress disorder.